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The State of Aging in Montana

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Informal Caregiving

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February 23, 2004

To: Interested Montanans

As another year has drawn to a close and a new year begins, it is with a great deal of pride and pleasure that the Senior and Long Term Care Division of the Department of Public Health and Human Services presents its annual report on "The State of Aging in Montana." The 2003 report is the fifth in a series of publications identifying the changing needs of Montana's aging population and what government is doing to meet current and future needs. The report is intended to serve as a tool for state and local government officials, policy makers, and businesses, as they prepare for life in an aging world.

We are an increasingly aging society. This poses challenges to us as individuals, family members, and communities as well as from a statewide perspective. This year's report looks at the issue of **informal caregiving** – families, friends and neighbors providing care to a loved one or friend so they can remain at home and in their communities. These informal caregivers are the backbone of the long-term care system, yet all too often they have gone unrecognized and have received limited support in their efforts. This report looks at recent efforts at the federal, state and local level to identify caregiver needs and to recognize the need for support to this component of the long-term care service delivery system.

"The State of Aging in Montana" reports continue to emphasize our need to prepare now for the dramatic demographic changes that are coming. These are challenges that we simply cannot ignore, not as a society or as individuals. By planning and taking positive steps now, we can increase the quality of life for current and future generations, young and old alike.

I hope you enjoy reading the report as much as we have enjoyed producing it.

Sincerely,

Kelly Williams

Kelly Williams, Administrator
Senior and Long Term Care Division

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2003 STATE OF AGING REPORT

As each year passes, aging issues loom ever larger on the State's horizon. Oft-quoted demographic trends only reinforce what we are seeing all around us - we as a nation and a state are becoming increasingly older. This singular fact holds great portend to our institutions of government, the fabric of our communities, and our families. In a little over two short years, the first Baby Boomers will turn 60 years of age and be eligible for services under the Older Americans Act. How well we age depends on what steps we begin to take now. This is the driving premise behind the State of Aging in Montana reports.

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MAP OF MONTANA'S AREA AGENCIES ON AGING

2003 STATE OF AGING REPORT OVERVIEW

In 1995, 13.1% of the State's population was 65 years of age or older, giving Montana the 23rd highest proportion of elders amongst all states. The 2000 Census revealed that at 13.4%, Montana had increased to the 14th highest percentage of people 65 years of age or older in the nation. As the Baby Boom generation (those born between 1946 and 1964) reaches retirement age, the growth of the elderly population is expected to accelerate rapidly. The proportion of Montana's population over 65 is expected to increase to 24.5 percent in 2025, giving Montana the 3rd highest proportion of elders in the nation.[1]

While we are aging as a society, we are aging a lot faster in Montana.

Beginning in the mid 1990's, the Senior and Long Term Care Division of the Montana Department of Public Health and Human Services (DPHHS) began looking into the effects that aging population trends would have for Montana and its senior population. In 1995, DPHHS, in conjunction with AARP, published its first brochure on this issue, entitled the "Graying of Montana." In March 1999, DPHHS produced the first **State of Aging in Montana** to begin to look at how state government viewed the impending aging demographic trends. The report was well received by the 1999 Montana Legislature, which subsequently passed House Bill No. 275, amending Section 52-3-101 of the Montana Code, and requiring the DPHHS to produce a biennial report, with annual updates, on statewide and community issues related to aging.

The Aging Reports in 1999 and 2000 looked at how various departments of state government perceived aging trends could impact their individual department missions and what actions they were taking to address them. The 2001 Aging Report looked at the same issues for local governments and local aging programs. The 2002 Aging Report examined the impact of health care work force shortages on people's ability to receive care through community-based services.

The 2003 State Of Aging in Montana report focuses on the issue of **informal caregiving**. This important issue is being highlighted for several reasons.

- The topic of informal caregiving complements last year's report dealing with health care work force issues. Informal caregiving represents another method by which people get their long-term care needs met. Since there are not enough health care workers to meet the current demand in community and institutional settings, informal caregiving serves a critical workforce function. While most informal caregivers provide care by choice, some continue to provide care or get into providing care because of the lack of qualified formal caregivers.

- For someone who needs help to remain at home, informal caregiving represents an invaluable commitment by family and friends to provide help across a broad spectrum of tasks ranging from help with shopping or getting to medical appointments to help with feeding and bathing and beyond. Because of its informal nature, it happens in the privacy of the home and often goes unnoticed by the public at large. However, informal caregiving represents how the majority of people in this county receive long-term care.

- The report will establish baseline data for Montana as we begin our state's efforts to develop caregiver services under the National Family Caregiver Support Program, a national program developed to support informal caregivers.

- Caregiving is an issue that will have significant social and fiscal consequences for Montana and its growing elder population. Any decline in the prevalence of informal caregiving could have a significant impact on government supported health care programs and their budgets.

- Informal caregiving is intrinsically valuable because it strengthens family and community bonds.

DEFINING CAREGIVING

Caregiving is a global term that encompasses a large range of situations that cross medical conditions, age groups, care settings and personal situations. It is an important component of the long-term care system. Caregiving focuses on the basic need for assistance regardless of who or how it is being provided. Used in its broadest sense, it can cover formal caregiving settings ranging from institutional settings like nursing homes to Home and Community Based Services such as the Medicaid Waiver and the Personal Care Program to in-home services provided through the Aging Network. In its most intimate sense, it can be families, friends and neighbors taking care of their relatives and friends in their homes. It is the latter that this report focuses on.

Informal caregivers are individuals who provide care to a relative or friend (a care recipient) that allows them to remain in their homes and their communities. In this report, we have chosen to use the term informal caregivers because it is more inclusive - it is better at capturing the broader scope of the caregiving experience. It includes not only family caregivers, but also friends and neighbors as well. In a rural state like Montana, all these elements are important components of caregiving. For purposes of the 2003 State of Aging report, we are concentrating on informal caregiving that involves people who are 60 years of age or older.

Informal caregivers do not receive pay for the care they provide. This differentiates them from formal caregivers who usually work for an agency and receive pay to provide care.

Informal caregivers provide assistance to someone who is experiencing limitations in **activities of daily living** (ADLs) such as eating, bathing, dressing, toileting or ambulating and/or **instrumental activities of daily living** (IADLs) such as shopping, preparing meals, medication management, managing money, transportation or doing basic housework chores. Without assistance in these areas, care recipients would eventually have to move from their homes to a residential care setting where these services would be available.

Because of the chronic nature these limitations in ADLs and IADLs cause, informal caregiving situations tend to be long-term situations. For many, changes in the health care system and in medical technology are pushing caregiving well beyond its bounds of just 10-15 years ago. New medicines and treatments that allow people to leave the traditional hospital setting and return home sooner, especially the elderly, have also thrust family caregivers into new roles. Now many caregivers must oversee the in-home use of sophisticated machines such as feeding tubes and respirators that before were the bailiwick of only highly trained health care professionals. Often caregivers must also administer multiple medications properly, often for several medical problems, or risk complications and the re-hospitalization of the care recipient.[2] Thus, to some

extent, the caregiving experience mirrors the trend seen in other areas of long-term care: more intense care that use to be provided in hospitals is now provided in other residential care settings and by other long-term care services.

Other important distinctions regarding caregiving that will be used in this report include:

- Primary caregivers who have the lead role in providing direct care to care recipients versus secondary caregivers who assist primary caregivers;
- Full time caregivers versus part time caregivers (who may be long distance caregivers);
- Caregivers who live with the person being cared for versus those that live separately; and
- Personal relationship to caregiver recipients: a spouse will approach the caregiving situation with a different set of expectations, history and needs from a child, relative or friend.

Formal caregivers are paid care providers or volunteers associated with a service system, such as personal care attendants, home health aides or public health nurses.

THE FACES OF INFORMAL CAREGIVING

The following examples illustrate the breadth of informal caregiving.

- A wife provides 24 hour care for her husband who has Alzheimer's disease;
- A son visits weekly to provide transportation to medical appointments and manages a checkbook for his father who has Parkinson's disease;
- Aging parents provide everyday assistance and supervision for an adult child with a developmental disability;
- A neighbor visits a friend with cancer to help her with shopping and run errands;
- An aunt moves in with her niece after suffering a stroke to get help with eating, dressing and bathing; and
- A mother caring for a son with traumatic brain injury from a car accident.

OVERVIEW OF INFORMAL CAREGIVING

Long-term care differs from other types of health care in that the goal of long-term care is not to cure an illness, but to allow an individual to attain and maintain an optimal level of functioning. Long-term care encompasses a wide array of medical, social, personal, and supportive and specialized housing services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition. [3]

When most people think of long-term care, they usually think of older people in nursing homes and hospitals, or government programs like Medicaid and Medicare. However, families, not facilities and government programs are the bedrock of long-term care. Informal caregiving by families and friends continues to be the way most people receive the long-term care services they need. It's family and friends assisting someone with a physical limitation or medical condition so they can remain at home. And it's not just older people that receive long-term care - people of all ages benefit from informal caregiving.

The most commonly quoted figure for the number of informal caregiving situations in the nation is 22.4 million households. This equates to about one in every four households in America that is involved in informal caregiving. The degree of caregiver involvement has remained fairly constant for more than a decade, bearing witness to the remarkable resilience of the American family in taking care of its older persons. This is despite increased geographic separation, greater numbers of women in the workforce, and other changes in family life. Thus, family caregiving has been a blessing in many respects. It has been a budget-saver to governments faced annually with the challenge of covering the health and long-term care expenses of persons who are ill and have chronic disabilities.[4]

There are many factors that contribute to the prevalence of informal caregiving. A combination of rugged individualism, a strong belief that families should take care of their own and an aversion to using formal services either because they are perceived as welfare programs or are seen as too costly all contribute to an atmosphere conducive to informal caregiving in Montana. For most care recipients, cost savings of informal caregiving are secondary to their ability to remain independent in their own homes.

Montana's rural nature heightens the need and importance of informal caregiving. In most rural communities, low population density, lack of medical services, infrastructure and trained staff as well as limited state and/or federal funding makes it difficult to develop and maintain many of the health care services that allow people to remain in their homes. Without the help of informal caregivers, most people needing care would be forced to move to someplace that had services or move into an institutional setting.

Care needs usually start with instrumental activities of daily living, such as help with transportation to medical appointments or shopping, or assistance with balancing a checkbook. As limitations increase, care needs progress to more personal types of care, such as eating, dressing and bathing. Friends and neighbors are more likely to provide assistance with instrumental activities of daily living than with the more personal activities of daily living. In informal caregiving situations, formal caregiving is usually a supplemental service used when a caregiver is unable to provide assistance or as caregivers burn out. When the need for care becomes too great, caregivers seek a residential placement to meet care needs of the care recipient.

CAREGIVING STATISTICS

THE MAGNITUDE OF LONG-TERM CARE SERVICES

The following statistics illustrate the magnitude of long-term care services and how informal caregiving compares to the overall long-term care continuum.

- Almost 100 million people in the United States have one or more chronic health conditions. Over the next twenty-five years, this number is expected to increase to 134 million Americans. These chronic conditions could potentially lead to caregiving situations.[5]

- The largest number of people who need long-term care are elders. Approximately 53% of people needing long-term care are people age 65 or older while 44% are working age adults between 18 and 64, and 3% are children under age 18.[6]

- There are 52 million informal caregivers providing care to a family member or friend aged 20 years or older who is ill or disabled.[7]

- 22.4 million households provide care to someone who is 50 years of age or older. This translates to nearly one in four U.S. households.[8]

- About 7.3 million informal caregivers provide help to people 65 years of age or older who are disabled and living in the community.[9]

- Informal caregivers provide 120 million hours of informal care per year.[10]

- 4.6 million people age 65 or older received home health care services in 1996 compared to 2.6 million under the age of 65.[11]

- Between 1997 and 1998, about 1,000,000 people received Medicaid personal care services or home and community based services through the Medicaid Waiver.[12]

- Nationally there were about 1,465,000 people in nursing homes in 1997. 91.5% of these people are 65 years of age or older.[13]

- Approximately 4% of the population over 65 years of age resides in nursing homes.[14]

LONG-TERM CARE COSTS

The following data provides a perspective on how informal caregiving costs compare to other components of the long-term care continuum.

- Public and private spending on long-term care services was estimated to exceed $127 billion in 1998. About $78.4 billion of this money was federal and state government funds. Individuals and families paid $34.5 billion out-of-pocket for long-term care services. The remainder was paid for by private insurance or other payers[15]

- The aging of the population is expected to result in a tripling of long-term care expenditures in the next 40 years from $115 billion to $346 billion annually.[16]

- In 1997, $83 billion was spent on nursing home care compared to $32 billion for home care.[17]

- If the services provided by informal caregivers had to be replaced with paid services, it would cost an estimated $196 billion.[18]

- Despite the trend toward community-based care as opposed to institutionalized care, only 18.2% of long-term care expenditures for the elderly are for community-based care.[19]

- In 1999, Medicaid paid $62.4 billion for long-term care services, 26.2% of which went to home and community based services.[20]

- In 1997, Medicare paid for 40% of the annual estimated home care expenditures, a little over 21% was paid from out-of-pocket, and Medicaid paid for approximately 15%.[21]

- Spending for home and community-based services through Medicaid Waiver programs averaged $485 per month per recipient compared to $2,426 per month for nursing home services.[22]

- Over two-thirds of the current health care dollar goes to treating chronic illness; for older persons the proportion rises to almost 95%.[23]

MONTANA LONG-TERM CARE STATISTICS

- In the 2000 census, Montana had about 360,000 households. Using national statistics, about 90,000 households in Montana could be engaged in caregiving.
- The Alzheimer's Association estimated that the total cost for providing informal care to people with Alzheimer's disease in Montana was $647 million.[24]
- The Medicaid Waiver program in fiscal year 2003 served 1682 people. This level of service has been consistent for the last three years.
- The Medicaid Waiver budget for 2003 was about $19,250,000
- Medicare home health served about 7900 people in Montana during calendar year 2000 at a cost of about $17 million.[25]
- The nursing home occupancy rate for the state fiscal year 2003 was about 78%. This means that there were about 5900 to 6000 people being served on any day in nursing homes in Montana.
- Medicaid nursing homes expenditures for state fiscal year 2003 were $122.3 million.
- About 61% of all nursing home bed days were paid for by Medicaid, while Medicare paid about 7% and all other sources like private pay and insurance accounted for 32%.
- For state fiscal year 2002 the personal care attendant program in Montana served about 3000 people and at a cost of about $30 million.
- Medicaid home health services served 540 people at a cost of about $780,000 during state fiscal year 2002.
- In federal fiscal year 2002, the Aging Network provided about 100,000 hours of in-home services to about 2000 seniors. In addition, Montana's Aging Network provided about 615,000 home delivered meals to about 6600 people.

THE SCOPE OF INFORMAL CAREGIVING IN AMERICA

Estimates of the number of caregivers range from **7 million** (3.4 % of the population) to **54 million** (26.6 % of the population) individuals. These differences are the result of the following variations in the definitions and methodology in collecting this data. Wherever possible, this report tries to provide data for the aging population as well as for the overall adult population providing and receiving informal caregiving.

VARIABLES AFFECTING CAREGIVING STATISTICS

- **Population for whom assistance was provided** - Because the need for care can occur at any age, there is a great variation in the age ranges used in studies. All studies target adults, but age ranges for care recipients can vary from 18 years or older to those 65 and older. Studies can also use a specific level of impairment in activities of daily living that care recipients needed to be included (such as needs help with at least 1 activity of daily living).

- **Population providing care** - These criteria focus on differing relationships of the caregiver to the care recipient (e.g., relatives versus others) and whether the caregiver and care recipient is living together in the same household or not.

- **Degree of help** - The focus here is on whether the caregiver provides any assistance at all versus providing regular assistance, as well as whether the caregiver is a primary caregiver or not.

- **Timeframe considered for having provided care** - These factors are structured in terms of how recently the care was provided (e.g., past month or past year).

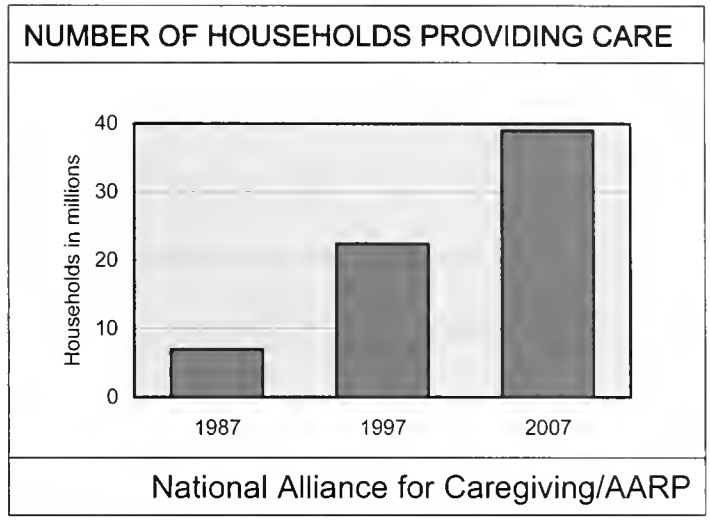
- **Data collection methods -** This factor looks at whom the data was gathered from (i.e., care recipients versus caregivers).

- **Unit of observation** - The two principle criteria for delivering services are either individual caregivers or households.

Administration on Aging: NFCSP Resource Guide 2003

HOUSEHOLD DATA

- More than 22.4 million households are informal caregivers, providing care within a 12 month period to a family member or relative 50 years of age or older who has at least one limitation in their activities of daily living. The number of households providing care between 1987 and 1997 tripled.[26]



- By the year 2007, the number of caregiving households in the U.S. for person's aged 50+ could reach 39 million.[27]

- 5 million of the 22.4 million households providing informal caregiving (22%) are providing care to a relative or friend who is 50 years of age or older and has some form of dementia.[28]

INDIVIDUAL CAREGIVER DATA

- There are 52 million caregivers providing informal care to a family member or friend aged 20 years or older who is ill or disabled.[29]

- About 7.3 million informal caregivers provide unpaid help to people 65 years of age or older who are disabled and living in the community. Of these caregivers, about three-fifths (4.2 million) are spouses and adult children, and the remaining two-fifths (3.1 million) are other relatives, friends and neighbors.[30]

- Estimates indicate that 25% of the entire American workforce provided informal care during 1996.[31]

- 51% of caregivers report that they are primary caregivers (i.e., they are the person who provides the majority of care).[32]

- Heavy-duty caregivers (those providing at least 21 hours of care/week), especially spousal caregivers, do not get consistent help from other family members. At least 75% of these caregivers are going it alone.[33]

PROFILE OF CAREGIVERS

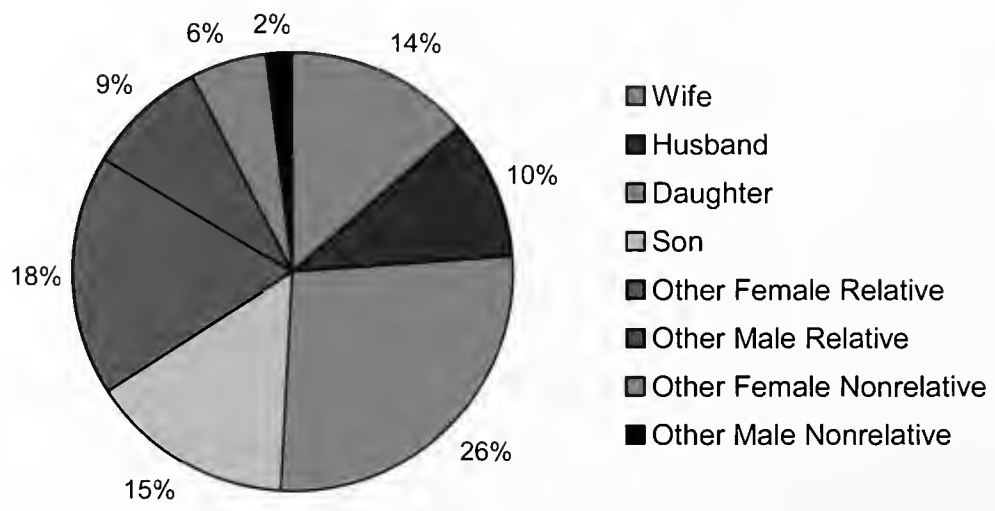
A profile of the typical informal caregiver would be a 46 year old married woman who is working outside the home, making $35,000, while taking care of an aged parent.[34] The following is a more specific demographic profile of who caregivers are.

- Nearly a third of caregivers are themselves over the age of 60. One quarter are between 65 and 75 years old, and another 10 percent are at least 75 years of age.[35]

- Approximately 75% of those providing care to older family members and friends are female.[36]

- Female caregivers spend 50% more time providing care than male caregivers.[37] The vast majority of caregivers are related to the care recipient they are caring for. Of caregivers who live with their care recipients, spouses account for about 62% of primary caregivers while adult children comprise 26%. Secondary caregivers are more likely to be adult children (46%) than spouses (16%).[38]

CAREGIVER RELATIONSHIP TO CARE RECIPIENT



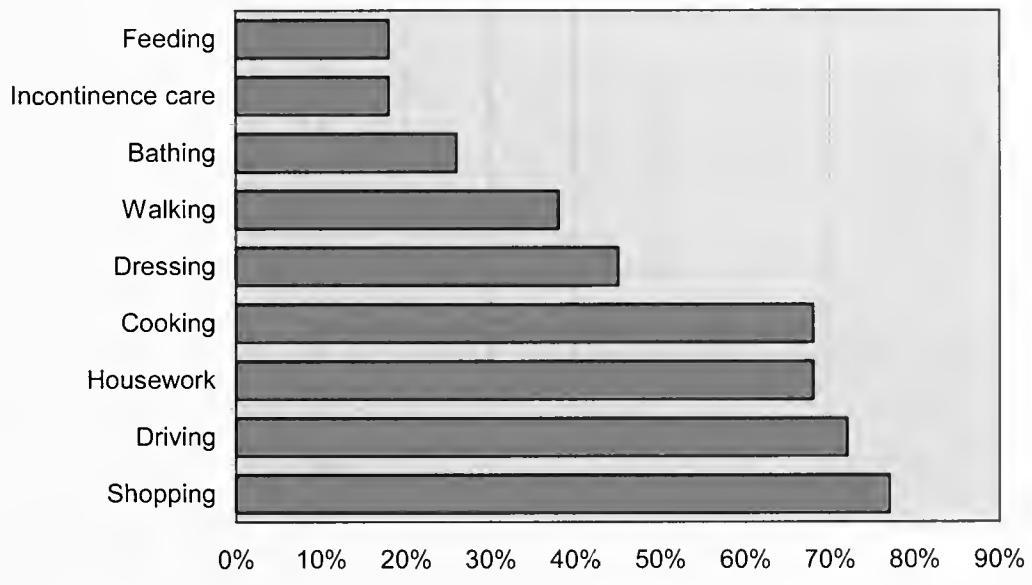
Family Caregiver Alliance: Selected Caregiver Statistics 2003

- Half of all caregivers are employed on a fulltime basis.[39]
- 51% of caregivers live in the same household as the care recipient.[40]
- Of those caring for someone 50 years of age or older, the average age of the informal caregivers is estimated at 46.[41]
- Caregivers of people aged 50 or older spend an average of 17.9 hours per week providing care. This figure increases to 20 hours per week among those providing care for individuals aged 65 or older.[42]

TYPE OF CARE PROVIDED BY CAREGIVERS

Older persons were more likely to receive help from caregivers for instrumental activities of daily living (IADLs) than for activities of daily living (ADLs). As illustrated in the table below, all IADLs showed higher rates of assistance than any of the ADLs.[43]

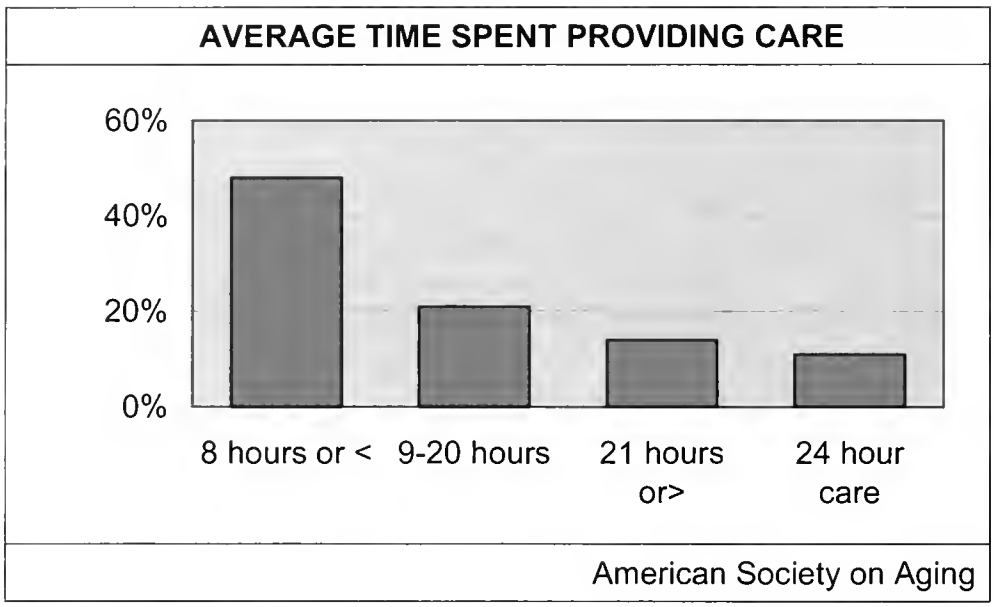
ACTIVITIES PERFORMED BY CAREGIVERS



A Portrait of informal Caregivers in America 2001 RWJ

Two thirds of caregivers provide assistance with activities of daily living[44]. Of those

- 19% provide assistance with 1 ADL
- 15% provide assistance with 2 ADLs
- 33% provide assistance with 3 ADLs



Unlike most formal caregivers, informal caregivers provide care around the clock - at nights, on weekends and holidays, and on demand.

- 80% of informal caregivers provide care 7 days a week.[45]
- On average, caregivers provide about 18 hours of help a week. This figure increases to 20 hours per week for care recipients aged 65 and older.[46]
- Informal caregivers spend an average of 4.5 years providing care.[47]
- 20% provide care 5 years or longer.[48]
- The percent of paid caregivers increased with age: among those receiving help, persons 85 years of age and over were 1.4 times as likely to have paid caregivers as persons 70-74 years of age.[49]
- The majority of persons receiving help (56 percent) received it from a single caregiver. The number of caregivers rose with age: among persons 70-74 years of age who received help, 63 percent received it from one caregiver. Among persons 85 years of age and over receiving help, only 44 percent had one caregiver. At each age, women had more caregivers than men.[50]

CAREGIVER STRESS

Informal caregivers face substantial stresses and burdens as a consequence of caregiving obligations. Prolonged caregiving can adversely affect one's physical and psychological health, current and future employment status and earning capability, ability to balance the needs of older parents and younger family members, and the ability to meet personal needs.[51] The following are some of the findings regarding care stress.

- Studies show that among caregivers, an estimated 46%-59% are clinically depressed. Approximately 49% of female caregivers and 31% of male caregivers experience depression as a result of caregiving. Among spousal caregivers, 21-25% of husbands and 50-52% of wives are depressed.[52]

- Caregivers use prescription drugs for depression, anxiety and insomnia two to three times as often as the rest of the population.[53]

- Almost one in five caregivers (22%) have been told by a health professional in the last 12 months that they have depression, nearly twice the rate in the general population.[54]

- More than half (55%) of all caregivers feel isolated. Feelings of isolation increase with the duration of caregiving.[55]

- Fifty percent of all caregivers feel that the burden of caregiving is "frequently" or "sometimes" too much to handle.[56]

- Stress in family caregivers is inversely correlated to income: the less income a caregiver has, the more stress he or she is likely to experience.[57]

- Older persons who lose a spouse respond differently based on whether or not they had cared for their spouse. Those who had provided care and suffered from stress as a result of their caregiving actually showed improved health behaviors and no increase in distress as a result of their spouse's death. Those who had not acted as a caregiver responded to their spouse's death with an increase in depression and weight loss.[58]

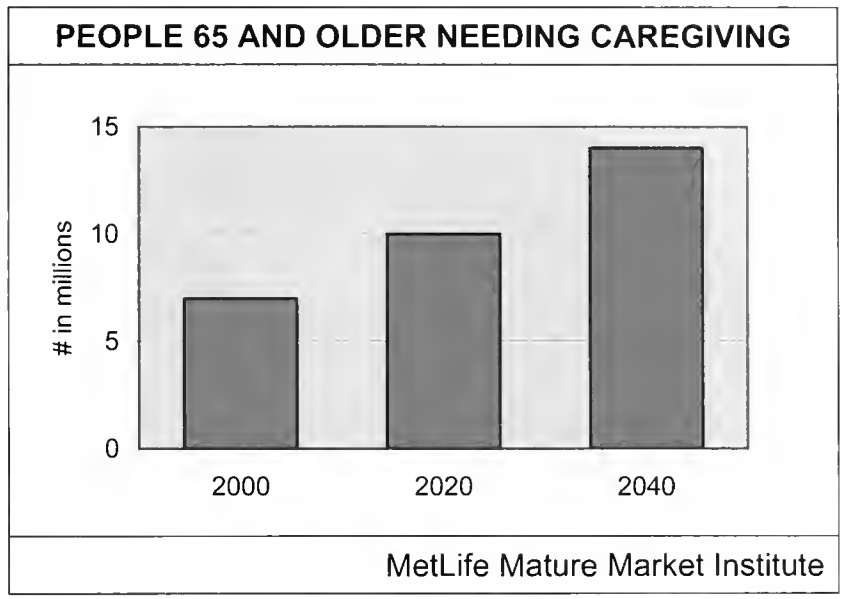
LONG DISTANCE CAREGIVERS

As families become more dispersed across the country, long distance caregiving is becoming an increasing reality for many relatives. This phenomenon brings unique challenges to the caregiving arena. The greater the distance, the more likely that the long distance caregiver will have to arrange for services rather than provide them directly. Pressures to re-locate the care recipient or seek institutionalization increase as well.

- Nearly 7 million Americans are long-distance caregivers for older relatives (i.e., they travel a distance of one hour or more between the caregiver and older adult needing assistance).[59]
- The average travel time for these caregivers to reach their relatives is 4 hours.[60]
- About half of all long distance caregivers spend 10 hours or more providing care.[61]

PROFILE OF CARE RECIPIENTS

- As the number of senior citizens increases, the prevalence of informal caregiving will grow. In 2000, more than 7 million older adults have long-term care needs. More than 10 million will have such needs by 2020 and 14 million by 2040.[62]



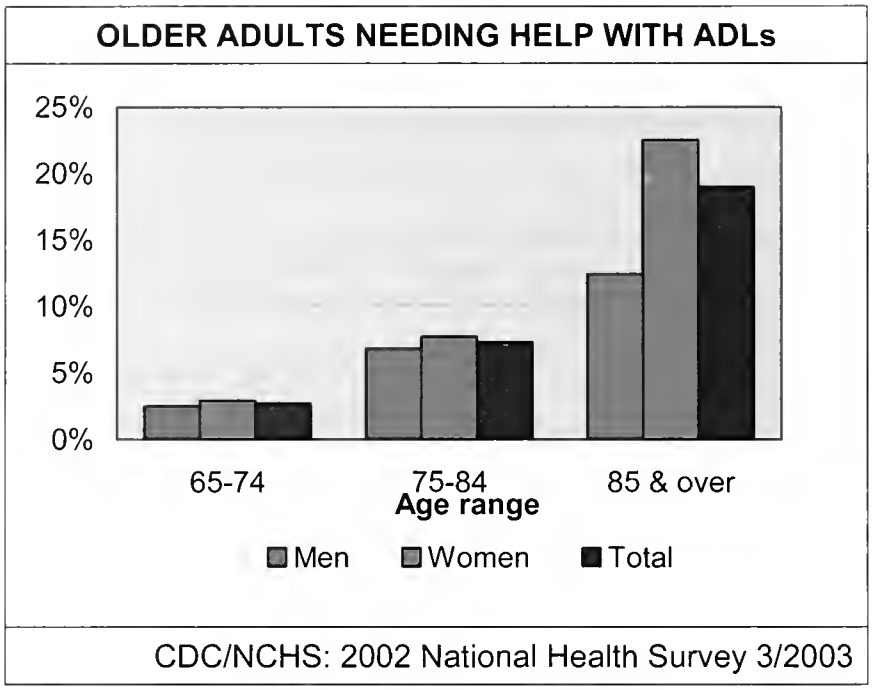
- 40% of the older population with long-term care needs are poor or near poor (with incomes below 150% of the federal poverty level).[63]

- 65% of older persons with long-term care needs rely exclusively on family and friends to provide assistance. Another 30% will supplement family care with assistance from paid providers. Only 5% rely exclusively on paid help.[64]

- Informal caregiving provided by family and friends can determine whether an older person can remain at home or not. In fact, 50% of the elderly who have a long-term care need but no family available to care for them are in nursing homes, while only 7% who have a family caregiver are in institutional settings.[65]

- There are about 1.5 million persons over the age of 65 residing in nursing homes compared with 1.6 million elderly who have similar personal assistance needs but live in their own homes or in the homes of their adult children or other family caregivers.[66]

- 480,000 adults with developmental disabilities live with parents over age 60. [67]

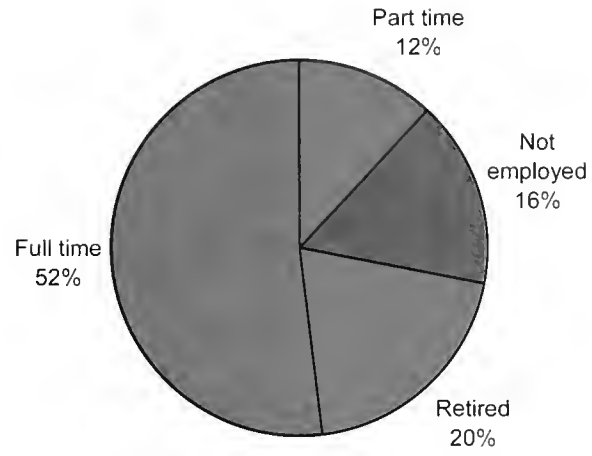


- 6% of all adults age 65 or older need help from another person with activities of daily living (such as eating, bathing, dressing, or walking). Adults 85 years of age or older are more than 6 times as likely to need assistance with activities of daily living as people who are 65-74 years of age. For this age group, women were more likely than men to need assistance.[68]

CAREGIVING IN THE WORKPLACE

Informal caregiver issues affect both employees and employers. This issue will only increase in its magnitude as the number of informal caregivers increases. Currently, nearly two thirds of all caregivers who are providing care to a person 50 years of age or older are employed at the same time they are providing care.[69] From an employee perspective, there are a number of caregiving issues that affect employment as well as on the job performance. Caregivers have more stress-related illnesses, utilize company health care plans more, and need more flexibility in their work schedules to meet their caregiving duties. Working caregivers can also face significant losses in career development, salary and retirement income, and incur substantial out-of-pocket expenses because of their caregiving obligations.[70]

EMPLOYMENT STATUS OF CAREGIVERS



National Alliance for Caregiving/AARP1997

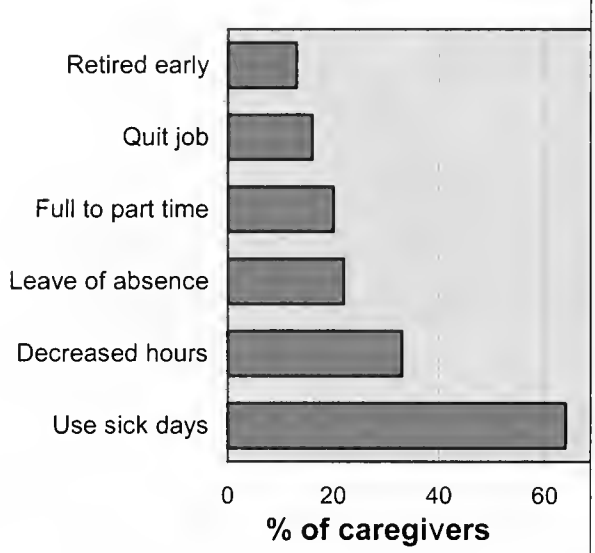
The MetLife Mature Market Institute report, *The Juggling Act: Balancing Caregiving and Work and the Cost Involved* highlighted the conflicting demands of work and eldercare. Caregiving responsibilities can mean lost opportunites for job advancement and job training. A total of 40% of the survey respondents in the MetLife survey reported that caregiving affected their ability to advance in the job in one or more of the following ways:[71]

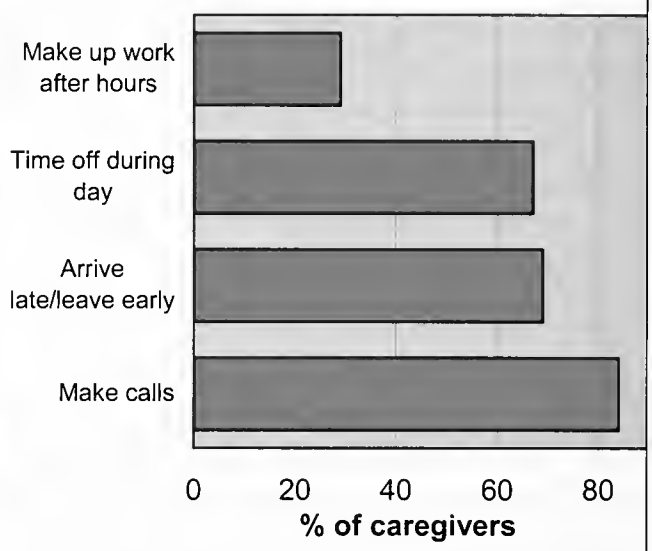
- 29% passed up a job promotion, training or assignment
- 25% passed up a job relocation or transfer
- 22% were not able to acquire new job skills
- 13% were not able to keep up with changes in necessary job skills

As a result of their caregiving, informal caregivers are estimated to each lose an average of $25,494 in Social Security benefits, an average of $67,202 in pension benefits and an average of $566,433 in wage wealth. Combined, the result is a loss of $659,139 over the lifetime.[72]

Both working men and women caregivers report needing to modify their work schedules and miss some work as a result of caregiving. Among working caregivers caring for a family and friend aged 65 or older, two-thirds report having to rearrange their work schedule, decrease their hours or take an unpaid leave in order to meet their caregiving responsibilities.[73]

FORMAL AND INFORMAL ADJUSTMENTS TO CAREGIVERS' WORK SCHEDULES





The Met Life Juggling Act Study November 1999

IMPACT ON WORKER HEALTH[74]

- Almost 75% of employed caregivers say that caregiving has had a negative impact on their health, with more than two in ten reporting significant problems.
- Of those reporting a negative impact on health, nearly half cited additional visits to a health care provider.
- Employed caregivers' use of prescription drugs is 2-3 times that of non-caregivers.

IMPACT ON CAREGIVERS' PERSONAL LIFE[75]

- 25% of caregivers report significant emotional stress; 44% report that caregiving has caused physical strain.

- Caregivers report average out-of-pocket expenditures of $171 per month for medications, groceries, home modifications, and other expenses for their relative.

- More than four in ten caregivers report that they have less time for other family members and an equal number say that they have had to give up vacations, hobbies, and other activities.

When employed caregivers were asked to identify what would make their caregiving duties easier, they identified the following: [76]

- Easy and simple process to access resources/services
- Management and/or coordination of care and services
- Ease of time restraints and stress relief
- Respite from their responsibilities
- Consultation and referral
- Education and support
- Flexible hours or telecommuting
- Financial assistance

COSTS TO BUSINESS ASSOCIATED WITH CAREGIVING

Similar to childcare, the growing need for informal caregiving presents companies with a new reality - caregiving workers who must juggle multiple demands on their time, energy and attention. Currently about one out of five workers are balancing work and caregiving. Seventy percent of employers feel that caregiving-related staffing problems have increased over the past 10 years, and 92 percent believe these problems will increase over the next 10 years.[77] This trend emphasizes why employers must become aware of caregiving issues for economic as well as human resources reasons.

According to the MetLife Mature Market Institute report *The Juggling Act Study: Balancing Caregiving and Work and the Cost Involved* the estimated cost of informal caregiving in terms of lost productivity to U.S. businesses is between $11.4 billion and $29 billion annually.

The major effects of caregiving on employee productivity fall into six major categories:

- Replacement costs for employees who quit due to their caregiving responsibilities
- Absenteeism costs
- Costs due to partial absenteeism
- Costs due to workday disruptions
- Eldercare crises
- Costs associated with supervising employee caregivers.

Using the $11.4 billion figure and the criteria above, the MetLife study determined that the annual costs to employers equals $1,142 per employee.

Because they constitute the largest number of caregivers, several studies have looked at the cost to employers specifically associated with women caregivers.

- The cost to businesses to replace women caregivers who quit their jobs because of their caregiving responsibilities has been estimated at $3.3 billion.[78]
- Absenteeism among women caregivers due to caregiving responsibilities costs businesses almost $270 million.[79]

- The cost to businesses because of partial absenteeism (e. g., extended lunch breaks, leaving work early or arriving late) due to women's caregiving has been estimated at $327 million. Caregiving-related workday interruptions add another $3.8 billion to the burden borne by businesses.[80]

One survey revealed how the stresses of eldercare affected employee productivity.[81]

- 56% of respondents said they were less productive at work
- 51% said they had to take time off during the work day for eldercare
- 30% reported being absent for a full day to deal with eldercare matters
- 10 percent of caregivers had to give up work entirely.

CAREGIVERS DEALING WITH ALZHEIMER'S DISEASE

An estimated 19-22% of families across the U.S. may be caring for an adult with a cognitive impairment. Cognitive impairments include a variety of diseases and disorders such as Alzheimer's disease, Parkinson's disease, stroke, head injury or AIDS dementia. Among these caregivers, four in ten name Alzheimer's or mental confusion as the main illness or problem. Although each disorder has its own unique features, family members and caregivers often share common problems, situations and strategies, regardless of the diagnosis.[82]

An estimated 4.5 million Americans have Alzheimer's disease, according to data based on the number of cases detected in an ethnically diverse population sample and the 2000 U.S. census. Using these criteria, projections are that by 2050, the number of Americans with Alzheimer's could range from 11.3 million to 16 million, with a middle estimate of 13.2 million. The prevalence of Alzheimer's disease doubles every five years after age 65, and nearly half of all people age 85 and older are thought to have some form of dementia.[83]

Informal caregivers providing care to a person with Alzheimer's disease tend to face a greater burden of care than other caregivers. This is due to the fact that as the disease progresses, persons with Alzheimer's disease tend to need around the clock supervision and are less able to assist in providing their own care. These caregivers spend more time in the day-to-day tasks of caring and provide the most difficult type of care. It is not just the amount of time they spend but the type of care they provide that makes Alzheimer caregiving so intense.

The following are some facts from the Alzheimer's Association/National Alliance for Caregiving report *Who Cares? Families Caring for Persons with Alzheimer's Disease* that compare Alzheimer's disease caregivers to other caregivers.[84]

- Almost nine in ten Alzheimer's caregivers are giving care to a relative - most commonly a parent, but often a grandparent, aunt or uncle, a parent in-law or a spouse.

- Because of a greater need for supervision, they are more likely to be living with the person for whom they are providing care. Caregivers reported that 53% of care recipients who had Alzheimer's disease were living with a caregiver.

- They are twice as likely to be providing more than 40 hours of care each week.

- Nearly three-fourths of Alzheimer's caregivers have been providing care for at least a year, and 38% have been providing care for more than 5 years.

- They are twice as likely as other caregivers to be providing the highest levels of care. 73% of caregivers age 65 and over are providing the highest levels of care.

- Nearly seven out of ten Alzheimer's caregivers help their care recipient with at least one Activity of Daily Living (ADL). Most commonly, they help with dressing the care recipient or helping him/her get in and out of beds and chairs. They are twice as likely to be dealing with incontinence (one of the biggest challenges of caregiving) and feeding.

- A majority of Alzheimer's caregivers provide assistance with each of the instrumental activities of daily living. At least two-thirds help with transportation, housework, grocery shopping, preparing meals, arranging outside services, and managing finances, while just over half help with medicines. Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to help with meals, outside services, finances and medicines.

- They are more likely to be caring for someone who is using a wheelchair or uses a walker.

- The two most often mentioned difficulties of caregiving reported by Alzheimer's caregivers are seeing the progressive deterioration of the care recipient, and having high demands on their time.

- Alzheimer's caregivers are more likely than non-Alzheimer's caregivers to say their caregiving negatively affects the time they have for family members, the amount of time they devote to vacations and their own activities, and the physical or mental health problems they suffer.

- People with Alzheimer's disease live an average of eight years after diagnosis, although some people may live for as many as 20 years after being diagnosed.

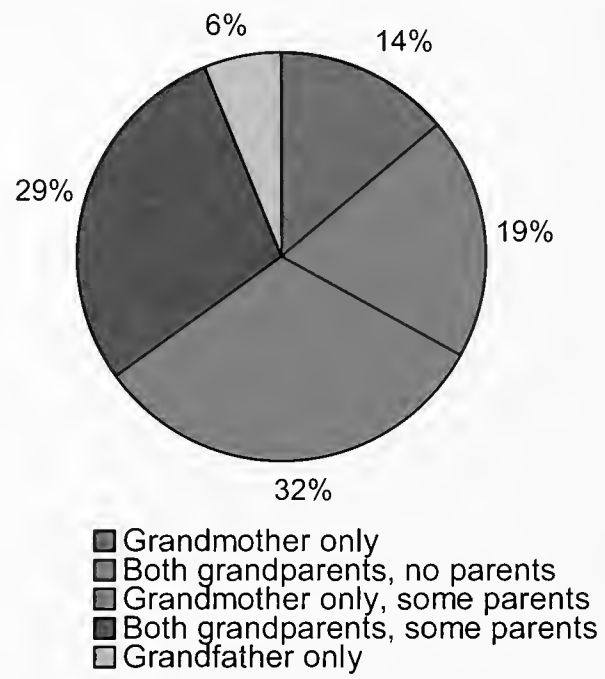
- 53-69% of people with dementia are out of bed at night, waking their caregiver and requiring supervision.[85]

GRANDPARENTS RAISING GRANDCHILDREN

The phenomenon of grandparents and other relatives raising children is nothing new. Over the last 25 years, however, the number of children being raised by someone other than a parent has increased dramatically, with the vast majority of these children being raised by their grandparents.

Since 1970 there has been an increase in all types of grandparent headed households. The most significant increase has been in those households where grandparents are the primary caregivers and no parent is present. Between 1990 and 1998, the number of these families increased by 53 %.[86]

TYPE OF GRANDPARENT HEADED HOUSEHOLDS



U.S. Census Bureau: 2000 Census data

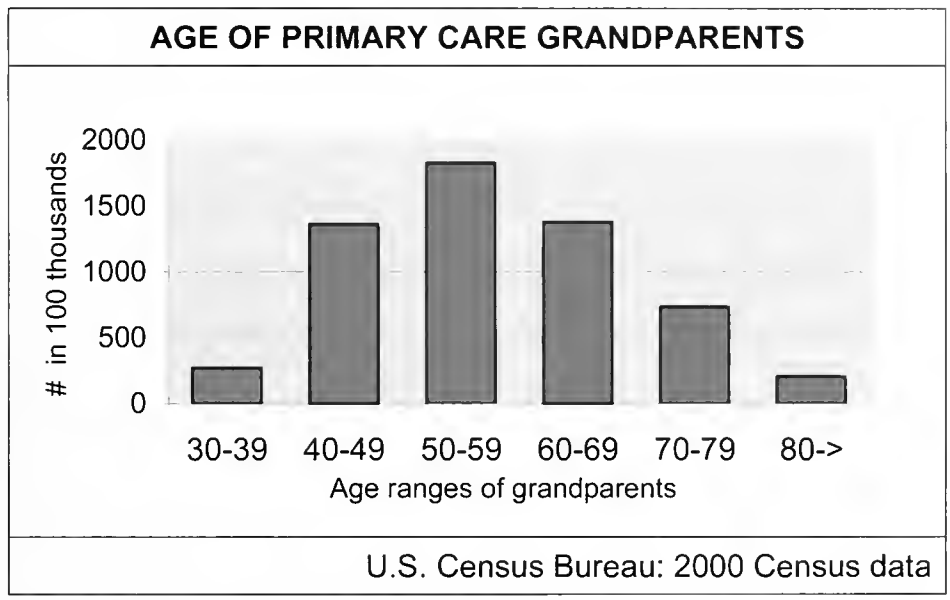
In the ten-year period from 1990 to 2000, there were over a million grandchildren nationwide who are living in grandparent headed households. Some of the factors that result in grandparents raising their grandchildren include alcohol and drug abuse, divorce, incarceration, unemployment, child abuse or neglect, HIV/AIDS, death of the parents, parents serving in the military and teenage pregnancies.

This overview focuses specifically on grandparent caregiving and does not include the significant time grandparents contribute to providing day care services for their grandchildren.

Grandparents raising grandchildren can face significant challenges related to their primary care role. These can include unplanned financial strains (especially for those living on a limited fixed income), coping with personal health care issues while trying to provide care to others, psychological stresses (such as depression) and decreased socialization with peers. Since most caregiving grandparents do not have any formal legal authority for their grandchildren, they also may face difficulties in their dealings with schools, health facilities and other agencies that may require proof of legal authority as a condition of providing services.

As a result of the increasing trend in grandparents raising grandchildren, Congress included language in the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, directing the Census Bureau to obtain information about grandparents who have primary responsibility for the care of their grandchildren. This represented the first time the Census Bureau collected specific information on grandparenting issues. The 2000 Census contained questions regarding whether grandparents were co-residing with grandchildren, if the grandparent had primary care responsibilities for their grandchild and the length of time they have had responsibility in order (to determine if the relationship was temporary or permanent).

2000 Census data indicate that the issue of grandparents raising grandchildren cuts across generations and is not necessarily a senior citizens issue. Census data is broken down into ten-year age cohorts, starting with grandparents aged 30-39 years of age and going all the way to age 80 and over. The largest age range is the 50-59 age range, followed by the 60-69 age range.



- According to the 2000 U.S. Census, there are currently 5.8 million children in the United States who are living in grandparent or other relative headed households, with or without parents present.

- Approximately 2.42 million grandparents raising grandchildren nationwide are 60 years of age or older.

- Approximately 9500 grandchildren age 18 or younger are being raised by grandparents who are 60 years of age or older in Montana. This represents about 4.1% of the total population of children 18 years of age and younger in Montana.

While the focus of this report are those grandparents who are 60 years of age or older, issues such as the legal status of grandparents in relation to their grandchildren, medical coverage for grandchildren and the cost of raising grandchildren are issues common to all grandparent caregiving situations.

HIGHLIGHTS FROM THE 2000 CENSUS DATA FOR THE U. S. AND MONTANA

	US	MONTANA
GRANDPARENTS OF ANY AGE WHO CO-RESIDE WITH GRANDCHILDREN		
Total number grandparents living in a household with one or more grandchildren under 18	5.77 million	11,100
% of grandparents living in a household with one or more grandchildren under 18	3.6%	2.1%
Total number grandparents 60 years of age or older who are living in a household with one or more grandchildren under 18	2.3 million	
GRANDPARENTS WITH PRIMARY CAREGIVING RESPONSIBILITIES		
Total number of grandparents who are primary caregivers for grandchildren living with them	2.42 million	6050
% of grandparents who are primary caregivers for grandchildren living with them	42%	55%
Total number grandparents who are age **60 or older** and are primary caregiver for grandchildren	1.69 million	1875
% of grandparents who are age **60 or older** and are primary caregiver for grandchildren	29.1%	31.1%
HOUSEHOLD DATA		
Number of households with individuals 60 years of age or older	4.1 million	
% of households with individuals 60 years of age or older	3.9%	

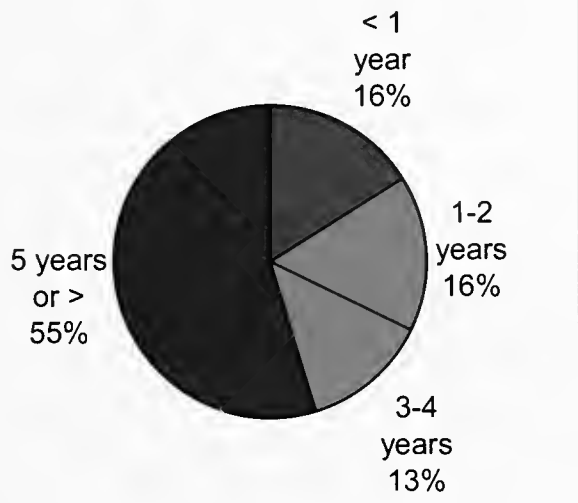
GRANDCHILDREN HIGHLIGHTS FROM THE 2000 CENSUS

CHILDREN LIVING WITH GRANDPARENTS	**US**	**MONTANA**
Number of children living with grandparents or other relatives	6 million	9,526
Number of children living with grandparents or other relatives with no parents present	2.1 million	
% of children living in grandparent headed households	6.3%	4.1%
% of increase in number of grandchildren in grandparent headed households	29.7%	53.8%

In terms of the percentage of total children living in grandparent headed households, Montana ranked 38th at 4.1%. However, Montana had the 9th largest increase in the number of grandchildren living in grandparent headed households from 1990 to 2000.[87] One factor that likely influences this rate increase is the higher percentage of Native American grandparents raising grandchildren. These statistics indicate that grandparenting issues will likely become more prominent as time passes.

Of the 2.1 million children living with grandparents who are primary caregivers, approximately 145,150 of them are in the foster care system. These children make up almost a quarter of the entire U.S. foster care population of 588,000 children.[88]

LENGTH OF TIME PROVIDING CARE



U.S. Census Bureau: 2000 Census data

Between July 2001 and March 2002, there were 2,063 children in Montana in out-of-home placements. Of these children, 492 (23.8%) were being raised in households where grandparents or other relatives were the primary caregivers.[89]

A total of 69% of all grandparents who co-reside with grandchildren do not have primary caregiving responsibility. Of the 31% of grandparents who have primary caregiving responsibility, 84% take care of their grandchildren for at least one year. Interestingly, when grandparents become the primary caregiver for their grandchildren, they tend to take on the responsibility for a long period of time. Over half of grandparents act as primary caregivers of their grandchildren for at least 5 years.

ADDITIONAL FACTS ABOUT GRANDPARENTS RAISING GRANDCHILDREN

- 77% of grandparents raising grandchildren are women.[90]
- Nearly one in five children (19%) living in households maintained by their parents lived in poverty in 1997. In contrast, more than one in four children (27%) living in grandparent headed households were impoverished.[91]
- About one in eight children (13 %) in parent headed households had no health insurance in 1997, whereas one in three children (33 %) living in grandparent headed households had no health insurance. The primary source of insurance coverage for children is through their parents' employers, thus making it more likely for children to be covered when one or more parents are living in the household than when they are not.[92]

Grandparenting issues were not originally included in the initial drafts of the National Family Caregiver Support Program. Senior advocacy groups lobbied Congress to include grandparenting in the NFCSP because of the growing scope of the issue and the need to target funds specifically to grandparent issues. Their efforts were successful. Currently, the Older Americans Act allows states to use up to 10% of their total NFCSP funds to support programs and services for relative caregivers 60 years of age who are providing care to children age 18 and younger.

To qualify for services, the following conditions must be met:

- The caregiver must be a grandparent, step grandparent or a relative of a child by blood or marriage who is 60 years of age or older;
- The older caregiver must reside with the child;
- The older caregiver must be the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary care of the child; and
- The older caregiver must have a legal relationship to the child, such as a legal custody or guardianship, or is raising the child informally. The majority of grandparents raising grandchildren fall into the "informal" category, since most grandparents do not normally seek guardianship or custody over their grandchildren.

CAREGIVER SUPPORT SERVICES

OVERVIEW OF FAMILY CAREGIVER SUPPORT PROGRAM

A growing body of evidence confirms that the provision of supportive services can diminish caregiver burden, permit caregivers to remain in the workforce, and enable people with caregiving needs to remain in community settings, possibly delaying or avoiding placements in institutional settings (like nursing homes and assisted living facilities). However, prior to 2001, there was not any comprehensive national approach to supporting and assisting the efforts of informal caregivers, especially those who were caring for seniors but were not 60 years of age themselves.

In the absence of a national program, several states (including California, New Jersey, Wisconsin and Pennsylvania) recognized the need for caregiver support and developed statewide programs. Congress eventually responded to the growing need to provide supportive services to informal caregivers by developing the National Family Caregiver Support Program (NFCSP) as part of the 2000 Reauthorization of the Older Americans Act. The goal of the NFCSP is to help caregivers early on in their caregiving careers to prevent burnout.

The National Family Caregiver Support Program is intended to be a highly visible, readily identifiable program that responds to the diversity of caregiver needs, while at the same time forging connections to the home and community based services (HCBS) system in each state. Since it is unlikely that the NFCSP alone will be able to meet the needs of all caregivers or respond to all the needs of an individual caregiver over the length of his/her caregiving career, it is vitally important to ensure the efficient and economical use of limited Older Americans Act (OAA) funds and to take advantage of other services that may support caregivers and help meet the needs of care recipients.[93]

The NFCSP represented the first major expansion of the Older Americans Act since the establishment of the nutrition programs in 1972. It is also the first time Older Americans Act funds are targeted to people who are under the age of 60. Traditionally, people 60 years of age or older have been the direct recipients of service under the Act. Equally important, it came with federal funding to help accomplish its goals. This is important to the Aging Network, since it is a relatively minimally funded program in terms of both federal and state funding.

The NFCSP targets two separate groups of caregivers:

- **Family caregivers:** Any adult family member or other individual who is an informal provider of in-home and community care to a person 60 years of age or older. This includes caregivers who are non-relatives, such as friends and neighbors.

- **Grandparents and relative caregivers** of children 18 years of age and younger. The caregivers must be a grandparent or step-grandparent of a child or a relative of a child by blood or marriage, be over age 60, live with the child, act as the primary caregiver of the child, and have either a legal relationship to the child or raise the child informally. Also included in this group are parents who are 60 years of age or older and are the primary caregivers of a child who has mental retardation or a developmental disability. Half a million people who have mental retardation or another developmental disability (or 12.5% of the total population with mental retardation or a developmental disability) are children or adults that live with parents over age 60.[94]

The statute also requires states to give priority consideration to persons in greatest social and economic need (with particular attention to low-income older individuals and older relatives caring for children or older adults with mental retardation or developmental disabilities).

NFCSP TARGET POPULATION REQUIREMENTS

	Any Informal Caregiver	Family Caregivers Age 60+
Caring for:	Older Adults	Children age 18 or younger
Priority Populations:	Those providing care to older individuals in the greatest social or economic need with particular attention to low-income individuals.	Older individuals providing care to children age 18 or younger with mental retardation or a developmental disability and older adults with mental retardation or a developmental disability.

The National Family Caregiver Support Program sets out limited, broad guidelines to meet the diverse needs of family caregivers, thus allowing states and area agencies greater flexibility and promoting innovation in service delivery at the local level. States are required to incorporate the NFCSP into the broader long term care service system in the state, including Medicaid programs, state-funded home and community based service (HCBS) program and Older Americans Act programs as well as any existing state-supported caregiver support programs.

Caregiver services are not limited to the NFCSP and its funding. Other long-term care providers (such as hospitals, nursing homes, and home health agencies) may also provide caregiver services (such as respite, adult day care and support groups) either on a private pay basis or through governmental funding such as Medicaid.

The National Family Caregiver Support Program is intended to offer a multifaceted system of caregiver supports, that includes, at a minimum, the following five service areas:

1. Information to caregivers about available services;
2. Assistance to caregivers in gaining access to supportive services;
3. Individual counseling, support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their roles;
4. Respite care to temporarily relieve caregivers from their responsibilities; and
5. Supplemental services, on a limited basis, to complement the care provided by caregivers.

Funding for the NFCSP has increased every year since its inception in 2001. Funding levels were $125 million in fiscal year 2001; $141.5 million in fiscal year 2002; and $155.2 million in fiscal year 2003. Most funds are allocated to states through a congressionally mandated formula that is based on a proportionate share of the age 70 and older population.

2002 AoA NATIONAL STATISTICS FOR NFCSP

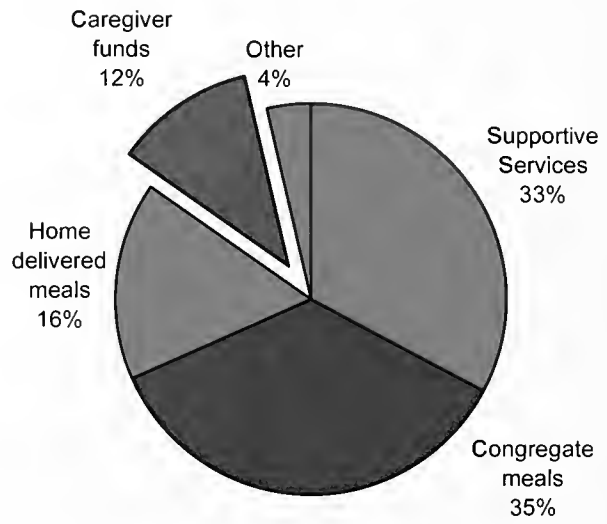
- 3.8 millions people received information about caregiving programs and services
- 436,000 caregivers were provided assistance with access services
- 180,000 caregivers received counseling and training services
- 70,000 caregivers received respite care services
- 50,000 received supplemental services

MONTANA CAREGIVER SUPPORT ACTIVITIES

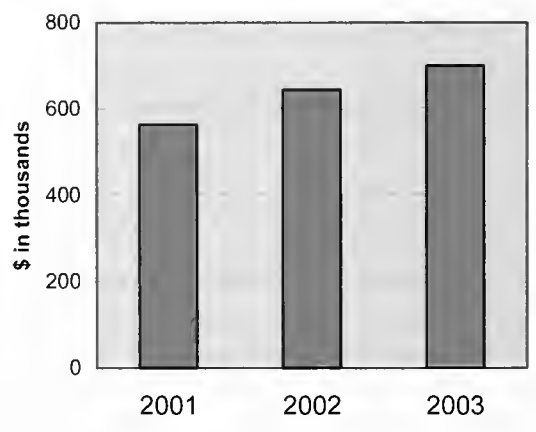
Montana is completing its third year of funding for the National Family Caregiver Support Program. NFCSP funding has allowed the Aging Network to augment existing services as well as provided the opportunity to expand services into previously underserved areas of need. NFSCP funding represents about 12% of the total federal funding the state received for services during federal fiscal year of 2002.

After in-direct costs, the State passes all NFSCP funds through to the Area Agencies on Aging (AAAs). The Older Americans Act sets some broad guidelines on how NFCSP funds can be used. Each Area Agencies on Aging has the flexibility to determine how they will use caregiver funds within the counties they serve. Some AAAs set broad area guidelines for the use of these funds based on input from their advisory board and local county councils. Other AAAs allowed individual counties to decide how best to use funds at the local level. Area Agencies receive funding for the NFCSP based on the state funding formula.

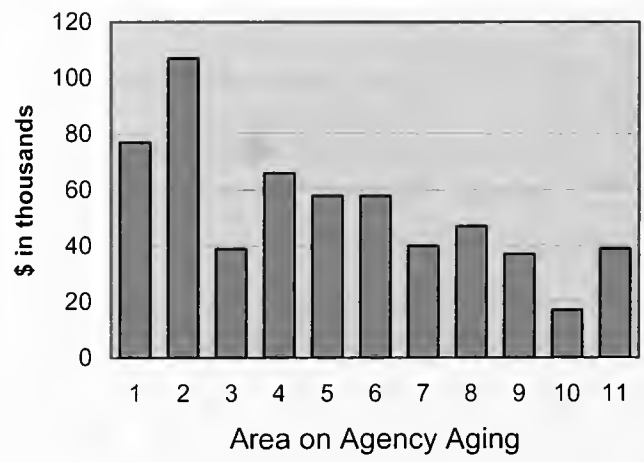
FEDERAL FUNDING FOR AGING SERVICES



FEDERAL $ FOR MONTANA NFCSP



NFCSP FUNDING BY AAA FOR FY 2002



For the first two years of NFCSP funding, funds were divided amongst 11 Area Agencies on Aging. In 2003, Area VII Agency on Aging, which served the state's 7 Native American Reservations, ceased operation. All federal funds, including NFCSP funds, are now distributed based on the state funding formula to 10 AAAs.

Funding for NFCSP has increased in each of the three years of its existence. During federal fiscal year 2003, NFCSP funding for Montana reached about $700,000.

The following are some of the major challenges Montana faces in developing local NFSCPs.

- Developing comprehensive programs with limited budgets is very difficult. When NFCSP funds are allocated across 10 area agencies, budgets at the Area level range from about $17,000 in Area 10 to $100,000 in Area II (see above). On a per county basis, the range of NFCSP funds goes from about $800 in Petroleum County to about $44,600 in Yellowstone County. Both coincidentally are in Area II. The median amount of NFCSP funds is $4250.

- In many areas, it is not financially possible to offer all of the five services, especially if services did not exist prior to the NFCSP. Local aging services providers must balance consumer needs against fiscal and programmatic realities. Low population density and geographic distances are constant barriers that many providers struggle with in developing and implementing new services.

- Reaching caregivers at a point when they are most likely to accept help and before they are in crisis.

- Developing ways of helping caregivers to self-identify with their role as caregivers and helping them recognize their need for help in their caregiver role.

- Reaching employed caregivers and employers of working caregivers, especially in rural Montana where most employers are small businesses.

- Reaching out to and serving grandparents. Since they are caring for children, most grandparents tend to look to children services rather than aging services for assistance and support in their caregiving role.

- Coordinating new NFCSP services with existing state programs while avoiding duplication of services and conflicts in program administration. Respite is the best example of this potential.

- Recruiting and retaining qualified staff to work in all NFCSP services.

- Developing viable payment strategies for services that make the services more sustainable, yet still affordable to caregivers. Most of the current aging services are provided on a voluntary contribution basis. Many agencies are unfamiliar or

uncomfortable with implementing alternative payment methods, such as slide fee scales. Additionally, aging programs tend to be a provider of last resort - they provide services to those not covered by government programs like Medicaid or private insurances.

- Collecting program data on caregivers, care recipients and services provided.

Every four years, the State is required to develop an aging service plan that identifies the needs of its aging population and formulations how these needs will be met. The 1999-2003 Montana State Plan on Aging was developed prior to the passage of the National Family Caregiver Support Program, so specific caregiver issues were not incorporated into the Plan. In the 1999-2003 Plan, Information and Assistance (I&A) services was one of the two priority services that were specifically targeted for improvement.

With passage of the NFCSP in 2001, the Aging Network took advantage of NFCSP funds to increase and improve I&A services statewide. Each Area Agency on Aging now has an Information & Assistance Coordinator in the Area office that oversees and coordinates all Information and Assistance efforts within the Area, including caregiver assistance. Many counties also added local Information and Assistance Technicians. Montana also has implemented a uniform statewide Information and Assistance data collection program that is accessed over the Internet. This will greatly enhance the delivery of services to caregivers while at the same time allowing better local and state level information management and analysis.

In public hearings and advisory committee meetings held to gather input to the 2003-2007 State Plan on Aging, caregiving issues were highest ranked and the most frequently mentioned issues. Given the diversity and complexity of caregiver issues, a broad range of initiatives was developed for implementation on a statewide basis through the 2003-2007 Plan.

The following areas of need were identified through the hearings process:

- Caregiver education and training
- Caregiver support groups
- Respite services
- Development of a caregiver advisory board
- Increase funding for caregiver services

To accomplish these needs, Montana's Aging Network will take the following actions:

- Work with the Governor's Advisory Council on Aging to develop a Caregiver Advisory Panel to provide focus, input, direction and coordination in developing statewide caregiver services.

- Foster the development of community solutions to caregiver needs. One example of this is the development of community care teams, where community coalitions composed of health care providers, the faith community, community organizations, the aging network, and other disability groups work together to develop unique local solutions to local caregiver needs.

- Work with groups such as the Alzheimer's Association - Montana Chapter or the Montana Choice Grant to develop and strengthen local support groups.

- Build on the current efforts to meet caregiver education and training needs. Vehicles for this include conferences, TV, written materials, newsletters, videos, and local trainings. Because individual caregivers have specific needs, additional education and training methods to meet these individual needs will be explored.

- Work with the Montana State University Extension Service, AARP and other groups to meet the training, support and service needs of grandparent raising grandchildren.

- Create a specific focal point on the Senior and Long Term Care Website for Caregivers to provide easier access and more complete information and resources.

- Develop a caregiver assessment process to identify caregiver needs and provide information and referral services.

- Increase data collection on caregiving services through the implementation of IRIS program (Information and Assistance Program data management software) and modification of MASTS (Montana Aging Services Tracking System). This will allow better analysis and targeting of services.

Over the last three years, efforts regarding the NFCSP have resulted in the development of new partnerships. The best example of this is in the provision of respite services. Because of the limited funds, Area Agencies and County Councils on Aging historically have not been able to develop respite programs on their own. In most places, there is not enough demand for the service to sustain a freestanding program. Thus, aging programs have teamed up with other health care providers such as nursing homes, home health agencies, human resource development councils and lifespan respite programs to offer some level of service. In another collaborative effort, they are

working with the Extension Service and AARP to provide grandparent support groups and the Alzheimer's Association to provide caregiver support groups.

To improve access to services, the Aging Network developed several new outreach efforts. Since this is a new area of services, education and outreach to caregivers was deemed especially important and received a lot of initial attention. All aging educational activities have had a caregiver component since the establishment of the NFCSP. The main theme for the 2001 Governors Conference on Aging focused on informal caregiving. Every subsequent aging conference has had a specific caregiver track. The state produced aging television program and aging newsletter also have developed regular sections on caregiving issues.

The following table shows which specific NFCSP programs each Area Agency on Aging has chosen to develop within their area. Because information and assistance programs are two separate activities under the NFCSP but usually performed Information and Assistance Technicians and Coordinators at the local level, these two activities are combined in this table.

CAREGIVER ACTIVITIES BY AREA AGENCY ON AGING FOR 2003					
AAA	Respite	ADC	I&A	CM	Supplemental services
1	■	■	■		SN, HDM, Trans
2	■		■		
3	■	■	■		
4		■	■		SN, HM
5	■	■	■		SN ,HC,HM
6	■		■	■	
8	■				
9	■		■		
10	■				SN
11			■		
TOTAL	8	4	8	1	4

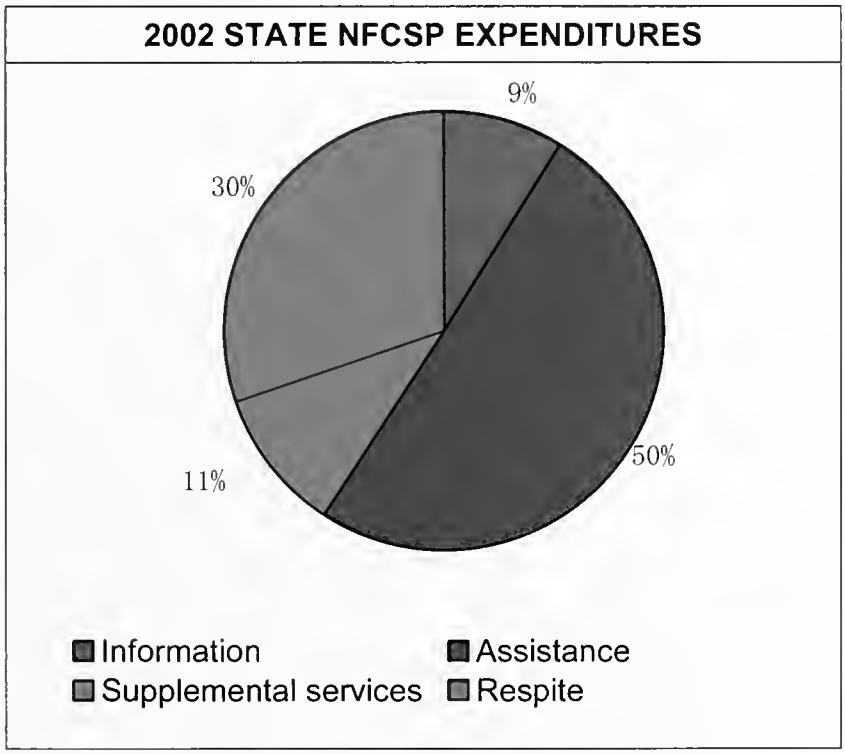
ADC = Adult Day Care services
I&A = Information and Assistance services
CM = Case management services
SN = Skilled nursing services
HM = Home maker services
HC = Home chore services
HDM = Home delivered meals
Trans = Transportation services

Note: Area 7 data is not included here. This was the Area Agency that served all seven Native American Reservations until it was dissolved in 2003. All the Reservations are now a part of the Area Agencies where they are geographically located.

The following table shows the units of services and the number of people served by the Aging Network in Montana for the federal fiscal year 2002 (October 1, 2001 through September 30, 2002).

	UNITS OF SERVICE	PEOPLE SERVED
Information	2400 contacts/events	3500
Assistance	6000 contacts	3600
Counseling/Support /Training	20 meetings	35
Respite	9100 hours	550
Supplemental services	1400 hours	100

Finally, the graph below shows the amount of NFCSP funds spent statewide during federal fiscal year 2002. No funds were reported as being spent in the area of Counseling, Support Groups and Training. Some activities did occur in this area, but staff costs were covered under other NFCSP areas (such as information and assistance) or the efforts were of a collaborative effort.



It should be noted that most of the services provided under the NFCSP are not revenue generating services. The only potential revenue sources are from respite and supplemental services, where cost sharing is allowed. However, few programs use this option at the current time.

FAMILY CAREGIVER SUPPORT PROGRAM SERVICES

The following is a detailed description of each of the five service areas targeted by the National Family Caregivers Program and an overview of how the Aging Network in Montana is providing services in each area.

1. INFORMATION Two components	**Group services** including public education, provision of information at health fairs and other similar designations as determined by the state. **Outreach** - Interventions for the purpose of identifying potential caregivers and encouraging their use of existing services and benefits.
2. ASSISTANCE Two components	**Information and assistance services**: This service provides current information on opportunities and services available; assesses the problems and capacities of the individuals; links the individuals to the opportunities and services available; to the maximum extent practicable, ensures that the individuals receive the services needed, and are aware of the opportunities available to the individuals by establishing adequate follow-up procedures. **Case management services**: Assistance either in the form of access or care coordination in circumstances where the older person or their caregivers are experiencing diminished functioning capacities, personal conditions or other characteristics which require the provision of services by formal service providers. Activities of case management include assessing needs, developing care plans, authorizing services, arranging services, coordinating the provision of services among providers, follow-up and reassessment, as required.
3. COUNSELING/ SUPPORT GROUPS/ TRAINING	Provision of advice, guidance, and instruction about options and methods for providing support to caregivers in an individual or group setting.
4. RESPITE	Temporary, substitute supports or living arrangements to provide a brief period of relief or rest for caregivers. It can be in the form of In-home respite, adult day care respite, or institutional respite for an overnight stay on an intermittent, occasional, or emergency basis.
5. SUPPLEMENTAL SERVICES	Other services to support the needs of caregivers, as defined by the state. These services are provided on a limited basis, to complement the care provided by eligible caregivers.

The Information and Assistance Program is the focal point in the Aging Network for delivery of caregiver support services. Most of the duties outlined under the Information, Assistance and Counseling, Support Groups and Training categories of the National Family Caregiver Support Program coincide with the job description for Information and Assistance Coordinators and Technicians. Thus, when developing a plan on how to meet these NFCSP requirements, Montana decided to use the I&A Program as the main vehicle to accomplish tasks for the Program.

1. INFORMATION

Finding information on caregiving issues or assistance with caregiving needs in a timely manner is a huge challenge for both caregivers and service agencies set up to provide those services. There are two broad categories of information that caregivers typically seek: information about the chronic conditions care recipients have and how to meet care needs; and information about available services. Another important but usually unidentified need is information on meeting caregiver needs.

Providing caregiver services in Montana is complicated by the rural nature of the state. Cultural values affect how people in rural communities seek and accept services. People in rural areas learn to be self-reliant and don't readily ask for help. When they encounter delays or barriers in getting the help they need, they tend to make the best of the situation and move on. They are also likely to avoid taking the time and effort to ask for help again.

Various surveys document the difficulties informal caregivers in rural communities experience in attempting to secure the information, disease-specific education, skill training, respite and on-going support necessary to care for a frail and impaired elder in the home. However, descriptive studies of caregiving in rural communities indicate that almost half of all caregivers do not receive assistance because they:

- Do not know they are eligible for caregiver assistance services;
- Are unaware that such programs exist in their community;
- Are too embarrassed to accept services they view as "welfare";
- Are reluctant to seek services unless there is a "crisis"; and
- Find existing services too geographically distant to be helpful.[95]

Often caregivers do not seek help because they do not identify themselves as "caregivers" - but rather see themselves as spouses, children or relatives stepping in and helping a loved one out because it's the right thing to do. Information and Assistance services must recognize that caregivers are customers in their own right. Caregivers have needs related to the care recipient's needs, and they have needs distinct from the care. I&A services must also recognize that the caregiver's personal needs and those of the person they are caring for will change over time. Since caregivers tend not to be connected with the formal service system, they may have a greater need for basic service information as well as need for health information about medical conditions and how to provide care for these conditions.

To reach caregivers at the "servable moment" rather than after it is too late, services must be effectively targeted and marketed. For example, offer respite services only

when caregivers reach the point at which they are providing extensive care and have identified themselves as caregivers will they become receptive (the servable moment) to respite programs. Different types of caregivers arrive at the servable moment for different reasons and use services only when they perceive the benefits to outweigh the monetary, emotional, or physical costs of using the service. Strategies to increase receptivity should be based on the understanding this.[96]

The goal of Information and Assistance services for caregivers is to increase education of caregivers to improve the quality and duration of the caregiving experience and raise awareness of the value of caregiving. Because the age range of caregivers is vast, services must be designed to service not only the elderly spouse providing care, but their children or other relatives as well.

MONTANA EFFORTS IN PROVIDING INFORMATION SERVICES

The Aging Network in Montana already has a fairly well developed network of public information methods that it uses to inform the public about aging issues. Caregiver issues have been integrated into all of these methods since the NFCSP has been established. Most of the activities in the informational area at the state level were accomplished without the use of NFCSP funds. These include:

- **The Senior And Long Term Care Division website - http://www.dphhs.state.mt.us/sltc/**

  The website now has a specific section dealing with caregiver issues, with caregiver information and links to other caregiver websites. It also lists resource information for in-home and supportive services. The website received over 500,000 hits in 2002 and over 900,000 in 2003. Long distance caregivers frequently use the website to research information for distant relatives and to get questions answered.

- **A long running cable television show on aging – Aging Horizons**
  This half-hour aging program is on 7 cable markets around Montana. Aging Services produces one show a week for airing. The show airs twice a day, for a week. Once a month, the television program devotes an entire show to a specific caregiver issue.

- **A long-term care informational packet - Your Future Is In Your Hands**
  Approximately 5,000 packets are distributed each year through the mail, at health fairs, conferences and through aging programs around the state. The long-term care packet added specific information on a broad range of caregiver topics two years ago. Topics including help deciding if home care is right for you, nutrition, hiring in-home help, paying for care, managing stress, special challenges of caregiving, and long distance caregiving.

- **A newsletter on aging issues – Aging Horizons.**
  The quarterly newsletter has 2-4 four pages of caregiver specific tips and educational material each edition. Approximately 1000 newsletters are distributed to all senior centers in the state, all recent attendees of the Governor's Conference on Aging, and key members of the Aging Network. The articles use materials from *The Comfort of Home Assistance News*, a monthly educational publication by CareTrust Publications of Portland, Oregon.

- **Annual Governor's Conference on Aging**
  Since the inception of the NFCSP, the conference has offered a caregiver track that provides basic education for caregivers and highlights innovative programs around the state. The 2001 conference had caregiving as its main theme. The keynote speaker for the conference was Maria Meyer, a national known author and expert in the area of caregiving. All conference attendees were provided a

copy of her book, The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers.

At the local level, I&A staff routinely provide or coordinate educational activities at senior centers and to senior groups. I&A staff do outreach to caregivers and seniors at health fairs, conferences, television and radio appearances and other meetings using both locally developed materials and materials developed at the state level.

The following are some of the highlights of local efforts to provide information and outreach at the local level:

- Area IV provides educational caregiver presentations based on The Comfort of Home book to senior centers and senior groups.

- Area XI developed resource packets for both caregivers and grandparents raising grandchildren. Packets include information on basic caregiving issues, services and management stress.

- Area XI has a resource room in the Area Office. It contains books and video resources that caregivers can use at the office or check out. They also have computers that caregivers can use to research information online.

- Area II requires its I&A staff to do a monthly presentation at each senior center in their area on senior or caregiver topics. They use extension staff and materials to develop presentations. Successful presentations are shared with other staff.

- There are a large variety of health and fitness fairs that occur around the state. The State Health Insurance Assistance Program and the Information and Assistance Program are part of a partnership of senior and health care organizations that have tried to identify and participate at each of these events around the state. Caregiver information and outreach has become an integral part of these efforts.

- Some Information and Assistance staff either participates in or coordinate local heath fairs. Representatives from Helena, Bozeman and Sidney developed a presentation at the 2002 Governor's Conference on Aging on developing and implementing health fairs.

2. ASSISTANCE

Under the National Family Caregiver Support Program, assistance has two components: Information and Assistance services and Case Management. The major form of assistance this section covers is the Information and Assistance Program (I&A).

Information and Assistance is a service that

- provides current information on available opportunities and services;
- assesses the problems and capacities of the individuals;
- links the individuals to the opportunities and services; and
- ensures, to the maximum extent practicable and by establishing follow-up procedures, that the individuals are aware of the opportunities and receive the services needed.

These are the same objectives as the NFCSP identified for the Assistance category. Caregivers are one of the many groups that are served under the I&A program.

Under the Older Americans Act, the Information and Assistance Program is one of the mandated access services that Area Agencies are required to provide. Information and Assistance program is the gateway to and backbone of the Aging Network. People have a general tendency to seek social services only when they need them. I&A services are usually the first contact that caregivers and others have with the Aging Network. Thus it is important that the service is provided in a professional, accurate and compassionate manner.

As our world and our lives get more complex, finding information and the help we need gets more difficult. Over the years, I&A services have become more sophisticated in order to meet people's basic needs for information and help. While technology can provide more options to those seeking information and/or assistance as well as making I&A Program more efficient, there is no substitute for direct person to person contact and help.

MONTANA EFFORTS IN PROVIDING ASSISTANCE SERVICES

Montana has had an Information and Assistance Program for over twenty-five years. The goal of the program has always been to have a local I&A Technician in each of Montana's 56 counties. This provides a local face to aging services - a focal point that is easy to access. Because of funding limitations, it has always been difficult to attain this goal. While there is not a local person in every county, there is a local presence in every county.

In the 1999-2003 State Plan on Aging, the Aging Network make I&A services a statewide priority. The Network established statewide goals that included increasing the professionalism of I&A services, increasing overall I&A coverage and improving data collection. To increase the professionalism and knowledge base of the program, a 3 day training and certification program was developed. This increased the core knowledge and skills of all I&A Technicians and established minimum job standards. Each AAA office also established an I&A Coordinator in every Area Agency office. The Coordinators are responsible for managing Area programs, coordinating local training, overseeing local I&A Technicians and ensuring that data collection duties are accomplished. Finally, a statewide database (IRIS - Information and Referral Information System) was implemented. It combines resource data, client demographic and client needs information. The database provides a uniform way to collect and share resource information statewide. The client tracking component allows the I&A Program to analyze who they are serving as well as their needs for service and any unmet needs.

The National Family Caregiver Support Program provided Montana the ability accelerate and strengthen the implementation of its Information and Assistance Program goals by supplying some needed funding. It allowed local programs to increase staff and resources to make the program more visible, professional and accessible.

The Information and Assistance Program is accessible through two statewide toll free numbers: caregivers can reach the state office through the toll free Citizens' Advocate number; local callers can access the Area program through a second toll free number. The single AAA toll free number is set up to automatically connect the call to the AAA office that serves the county from which they are calling.

3. COUNSELING, SUPPORT GROUPS AND TRAINING

Since each caregiving situation is unique, the support needs of caregivers vary depending on a host of different factors. Needs vary depending on the care needs and condition of the care recipient at the current time. Providing care for a person with dementia can present different challenges than caregiving for a person with a hip fracture. The support needs for children will vary from those of spouses. Needs vary depending on whether the caregiver is seeking information about how to deal with a medical condition versus seeking help finding services. They can vary depending on the preferences of the caregiver for the kinds of help that is provided (such as a preference for one on one counseling and support to a group support setting). And finally, caregiver needs for support will differ from the needs of the care recipient.

Support services must be flexible and diverse to meet changing needs of diverse caregivers. Support services can range from training, to the provision of caregiver counseling to support groups. Within each of these three broad groups there are a variety of models of providing service. Matching the mode of service to the needs and preferences of the caregiver at the time they are seeking help is the challenge of the service delivery system.

When defining the goals of the program it is important to decide whether one wants the program to reach out to all caregivers or to target particular subgroups of caregivers. Casting a broad net is appealing because it allows one to reach out and provide something for the largest possible group of caregivers. In local areas with limited resources or in sparsely populated areas, this may be the only option. Programs that invite broad participation, however, have to keep education and training activities at a general level. They are less likely than specialized programs to provide education and training tailored to the individual needs of caregivers. Some targeting variables to consider when designing programs include: whether the focus should be on prevention or remediation; the nature and extent of the care recipient's disability; the relationship of the caregiver to the care recipient; gender; race, ethnicity and socio-economic status; and special populations, such as grandparent caregivers.

There are many ways to educate and train family caregivers including:

- Single session community workshops and educational forums lasting anywhere from one hour to a full day, held in conjunction with other events such as a senior health fair, a senior expo, or similar event.

- Lecture series followed by discussion such as a neurologist may be asked to speak about the latest findings in the treatment of Alzheimer's disease, a pharmacist might be asked to speak about medication management, and/or a nurse may be asked to speak about home health management skills and assistive devices.

- Support groups that educate members by mutual sharing of information and by encouraging reciprocal help and self-help among members.

- Psycho-educational and skills building groups that help members by educating them about caregiving resources and skills and by teaching specific problem solving and coping skills.

- Individual counseling and training on topics such as caregivers or care recipients emotional reactions to chronic illness, family conflict resolution, personal care skills, problem solving skills for difficult caregiving situation, behavior management skills for care recipients with cognitive and emotional impairments, and/or information about caregiving resources and services.

- Family counseling about how to sustain their loved ones in both community and institutional settings, and how to interact with formal care providers.

- Care coordination and management educating, supporting and teaching family caregivers specific caregiving skills as well as specialized skills to manage particular mental and physical disabilities.

- Technology-based interventions including telephone-mediated groups, computer-mediated groups, video-conferencing and computer-assisted education and training.[97]

MONTANA EFFORTS IN PROVIDING COUNSELING, SUPPORT GROUPS AND TRAINING SERVICES

Prior to the advent of the National Family Caregiver Support Program, involvement in counseling, support activities and training on the part of the Aging Network was relatively minimal on the part of the Aging Network. Formal health care providers such as hospitals and home health agencies were more likely to be involved in these areas. Given the low level of activity in these areas and the limited funding available, the majority of services offered in these areas are being accomplished through collaborations with other agencies or in conjunction with information and assistance responsibilities.

Counseling

Most of the counseling efforts are done on an informal basis or in conjunction with provision of another service. Several counties that have contracts with public health nurses or home health agencies incorporate education and instruction into the assistance they provide to caregivers. This type of informal consultation could include a discussion on day-to-day management of behaviors, management of health issues, and/or management of medications.

Area XI has developed a care management service for caregivers. Through the Information and Assistance Program, caregiver needs and situations are assessed and necessary information and referrals are made. If caregivers need more in-depth assistance, a referral for an in-home assessment is made to a care management social worker who develops a one on one plan with the caregiver that looks at training or educational needs and evaluates stress and respite needs.

Grandparent Support

Because Older American Act services have historically been targeted to those 60 years of age or older, serving grandparents who are raising grandchildren under the age of 18 is something totally new to the aging network. To date, most of the efforts have been in the area of providing support groups. The Montana State University Extension Service and AARP have taken the lead in this area.

In mid 2002, Sandy Bailey, MSU Extension Specialist applied for and received a two year, $10,000 grant from the Brookdale Foundation to facilitate the development of grandparent support groups statewide in Montana. This represented the first statewide effort to develop services for grandparents raising grandchildren.

The MSU Extension Service developed partnerships with AARP, the Montana Department of Public Health and Human Services (including Aging Services), Montana PBS, Montana Child Care Resource and Referral, Montana Head Start Collaboration, Blackfeet Eagle Shield Center, Human Resource Development Councils, and the Office of Public Instruction to act as an advisory group, to coordinate services and resolve any service problems.

The Extension Service partnered with AARP to present three facilitator groups trainings (in Lewistown, Missoula and Miles City). The two-day training sessions cover topics such as legal issues, information on financial and medical assistance programs, the nuts and bolts of starting a support group, handling conflict with grandchildren, parenting the second time around, and networking with other support groups and agencies. A total of 66 people have attended the training.

In June 2003 four mini grants were awarded to assist communities in starting support groups. Recipients included Bozeman Senior Center, the Nurturing Center Child Care Resource and Referral in Kalispell, the Eagle Shield Center in Browning on the Blackfeet Reservation, and the Child Care Partnership Child Care Resource and Referral in Helena.

As a result of the trainings and mini grants, there are currently support groups for grandparents operating in the following communities: Kalispell, Bozeman, Columbus, Helena, Charlo, Great Falls and Browning.

Other grant activities relating to grandparents raising grandchildren include:

- Developing a newsletter
- A listserv for facilitators and individuals interested in GRG issues
- Providing facilitator update training
- Developing a legal guide for grandparents
- Developing a speakers bureau
- Evaluating the effectiveness of support groups

Caregiver Support

Historically, there have been few generic caregiver support groups for informal caregivers. There are a few support groups for formal caregivers. What support groups that do exist tend to form around disability specific issues, such as Alzheimer's disease, cancer, diabetes, or Parkinson's disease. These groups are usually run by a health care provider (such as a hospital or nursing home) or by state associations (like the Montana Diabetes Association or the Alzheimer's Disease Chapters).

With the advent of the NFCSP, the Aging Network is becoming more involved in informal caregiver support groups. Area Agency or County Council staff coordinates or assists in caregiver support groups in Billings, Great Falls, Mineral County, Plains, Thompson Falls and Hot Springs. Meetings combine socialization and support with educational efforts.

4. RESPITE

The primary purposes of caregiver respite are to decrease the individual and family stresses associated with caregiving, preserve family or caregiving relationships and to postpone the need for institutionalization of the care recipient. At a societal level, sustaining informal caregiving is likely to become increasingly challenging as the population ages, increasing the number of people needing long-term care and raising the age of the caregiving population. Some see an additional challenge for informal caregiving in the growing number of women participating in the workforce full-time.[98]

However, respite by itself is unlikely to address adequately a state's needs for caregiver support. While research suggests that respite leads to improvements in the mental health and quality of life of caregivers, it also shows that there remains a high prevalence of stress and depression among caregivers. Furthermore, no one form of caregiver support suits all situations. Studies demonstrate great diversity among caregiving situations, including differing family relationships, caregiver resources and stressors, care recipient needs and caregiving responsibilities.[99]

Respite services show benefits for caregivers when provided in sufficient amounts. Caregivers experience a cascade of stressful events that proliferate through every area of their lives. Given the enormity of the tasks they face, it is understandable that a few hours of respite a month would make very little difference. Regular and reliable respite care provided twice a week or more reduces care-related strain and improves well being.[100]

Because caregiving encompasses a wide variety of situations, respite can take many different forms. Sometimes, respite is provided on a more informal basis. A neighbor may spell a caregiver while the caregiver runs an errand. Caregivers may take a brief respite to go shopping while their loved one is getting formal care services from a personal care attendant, nurse, homemaker or other care provider. Respite can also take a more formal structure. A trained respite worker or respite volunteer may come into the home for an afternoon to allow the caregiver to take a break for purely social or emotional reasons. Assisted living facilities or nursing homes may provide institutionally based respite programs. These facilities may function like an adult day care program during daytime hours or may offer overnight or weekend respite, allowing caregivers to leave town for business or vacation, go into the hospital, or attend to an emergency. Additionally, respite programs may also be targeted to provide services to specific disabilities such as Alzheimer's disease or developmental disabilities.

While all these examples of respite provide caregivers with a break, for purposes of this report, respite services refer to those services provided in the home while facility based services are classified as adult day care centers. The main reason for this distinction is that federal reporting requirements divides respite services into these two categories.

POTENTIAL BARRIERS THAT MAY LIMIT CAREGIVERS USING RESPITE

- Caregivers tend not to seek respite services until the burden of caregiver is high. In a national study, 39% of caregivers reported needing respite care within the past 12 months, but only half of that number say they received it.[101]

- Caregivers tend to underutilize respite when they are receiving services. Studies in which sufficient amounts of respite were utilized show a reduction in care-related stress. Studies in which only small amounts of respite were provided reported little or no benefits to caregivers.[102]

- Caregivers tend to perceive the cost of respite as expensive. Many are trying to preserve care recipient funds for more catastrophic events such as nursing home placement or a catastrophic medical bill.

- Many caregivers are worried about turning over the responsibility of care to someone who may not know the care recipient well or can't do the job as well.

- Going through all the logistics and bureaucracy to get respite set up can pose too many barriers for some caregivers. Caregivers have reported some problems in delivery of in-home respite, including poorly trained and unreliable home support, and difficulties obtaining help during the hours they need it most They also prefer working with one person, not having different people come to the home each time.[103]

- There may not be a respite program where the caregiver lives. Some programs cannot meet all the needs of the caregiver, such as weekend, overnight or off hours respite.

- Caregivers may be unfamiliar with respite services or know how to find them.

- Some programs may have eligibility restrictions, such as age, diagnosis, income or level of disability, that prevent the care recipient from participating.

CHALLENGES FOR PROVIDERS OF RESPITE CARE

- Finding sufficient resources to offer the service. Demand for the service has to be sufficient to justify and sustain the program.

- Recruiting, training and retaining respite staff

- Bringing caregivers into the program at an earlier stage

- Creating sufficient flexibility to serve a range of caregiver situations and needs.

- Qualifying for a variety of payment sources.

MONTANA EFFORTS IN PROVIDING RESPITE SERVICES

Getting caregivers to recognize the need for respite is the biggest barrier to providing respite care. After this, the affordability of respite care is the biggest barrier. The NFCSP provides, for the first time, some minimal support to moderate-income families who are not Medicaid eligible and for whom there are limited or no state-funded caregiver support programs. Middle income families (who are above the eligibility limit for most other publicly funded programs) often cannot afford to pay for needed respite and other caregiver supports.[104]

Limited funding through the NFCSP for respite in Montana necessitates flexibility, creativity and coordination on the part of the Aging Network. Every Area Agency has identified respite as a service gap in their Area and most identified it as the biggest need. All Area Agencies have some involvement in providing some form of respite. Most Areas or counties have formed partnerships or collaborations to deliver either in-home respite or institution based adult day care. There are only a few programs that are run by aging services providers totally on their own. Even these programs tend to be mixed models - employing workers as homemakers, home chore or personal care attendants as well as respite workers.

The affordability issue for respite poses an interesting dilemma for the Aging Network. Most aging services are delivered on a voluntary contribution. Under the Older Americans Act, the Aging Network is prohibited from charging people for some services, such as Information and Assistance, Ombudsman services, congregate meals or home delivered meals. While the Act permits charging for respite services, few programs use this method. Programs site the affordability issue, consumers' expectations that the voluntary contribution system will be used or resistance within the Network to change. As a result there is little income to the Aging Network from respite services. What revenue that is collected usually goes to contractors (such as nursing homes) to offset their cost of care.

To date, only a few agencies in the Network have had to cap the amount of respite services an individual caregiver can use. Some informally educate caregivers about budgets. Agencies report that encouraging caregivers to use the program is a larger problem than limiting funds at this point in time. Based on the fact that Area Agencies see respite as the biggest unmet need, it is very possible that more capping may occur in the future as caregivers become more aware of the potential availability of the service.

Most of the respite that the Aging Network provides is short-term respite. This is mainly due to cost. A few area agencies (e.g., Area VIII and Area IX) offer overnight or weekend respite.

The following are some examples of the diverse methods being offered by the Area Agencies and County Councils to provide respite:

- There are currently only two Lifespan Respite Programs in Montana. Area I and Area II are collaborating with these programs to provide respite in about 8 counties in Montana. Lifespan Respite is a comprehensive approach to promoting respite by supporting local networks that increase access to respite. A network recruits and screens respite care providers (paid and unpaid); identifies training opportunities for respite care providers and helps establish new ones; helps clients to define their needs; connects clients with respite services and financing options; identifies, coordinates, and develops community resources for care; and assists with quality assurance and evaluation. One of the potential advantages of the Lifespan model is that it does not focus on a specific age group or disability.

- Lutheran Services in Chester has developed a volunteer respite program. They have 13 volunteers that provide respite, transportation, and do some home chore for caregivers needing respite. They get some funding through the County Council on Aging to pay for the cost of medical transportation as well as some reimbursement for respite providers. They also have an agreement that allows them to use the Council bus for transportation.

- In Great Falls, the Area Agency provides daytime respite through their Home Attendant Program. They contract with a Home Health agency for overnight respite and with a nursing home for weekend respite.

- Lake County Council on Aging (LCCOA) developed one of the first respite programs in the Aging Network in 2000. The program was developed in response to consumer demand for in-home respite services. The program does not provide overnight respite services or assistance with bathing. Liability issues and cost made overnight service impractical.

  Cost and sporadic usage of respite service are two factors that have made developing and maintaining a respite service a challenge in Lake County. The absence of regular work hours makes it difficult to recruit and retain staff. As a result, respite workers also perform homemaker duties. LCCOA conducts a nine-hour training program that workers must complete prior to providing services. There are currently about 10 people trained to provide respite services through the program.

  The respite program uses a sliding fee schedule to determine costs to clients. The use of the sliding fee schedule has increased the viability of the program. Costs for clients run from 50 cents an hour to about $11.00 an hour. During the last fiscal year, the program provided over 360 hours of respite to about 10 households. LCCOA has begun to screen for caregiver needs.

- Several areas (e.g., Area I, Area V and Area X) offer respite services in conjunction with another in-home service, like homemaker, home chore or skilled nursing. Sometimes the service may be delivered as respite and sometimes the caregiver gets a respite while the worker is delivering homemaker services or other services.

- Missoula Aging Services is partnering with Caring Circles, a faith-based respite program to develop respite services in Missoula. They have supported the program with staff time and by participating in a Town Forum initiated by the program. They have also developed a fact sheet they distribute to caregivers detailing facility based and home health programs that offer respite and the costs of their services.

ADULT DAY CARE

The adult day care model differs from respite in that it is provided outside the home, in a group setting or in a facility. Adult day care is usually a more structured service that offers a greater array of services than respite typically can. Adult day care can be used as out of the home respite for short-term intermittent periods. It can also be used as a place that caregivers take family members needing care while the caregiver goes to work. Facilities providing adult day care can include senior centers, assisted living facilities, nursing homes, or hospitals.

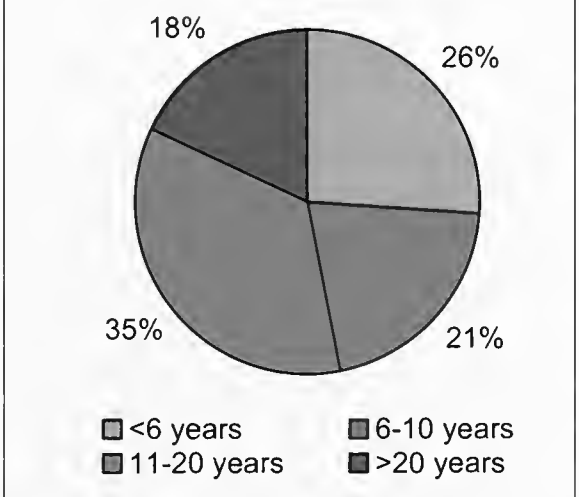
There are two basic models of care provided by adult day care centers: services based on a social model and services based on a medical model. Centers that offer services on the social model usually offer meals, personal care services, socialization, social services, health monitoring, caregiver support services, social activities and transportation. Centers that operate on the medical model usually offer therapeutic activities, medication management, nursing services, rehabilitation therapy, and medical services. Many facilities provide a hybrid of social and medical services. Some centers may also provide overnight, weekend and emergency services. Since they already employ professional nursing staff, health care facilities that provide adult day care (such as nursing homes and hospitals) tend to provide either the medical model or a hybrid model. Most senior centers and assisted living homes provide services based on the social model because they do not typically employ professional nursing staff.

Partners in Caregiving: The Adult Day Services Program at Wake Forest University School of Medicine conducted a census of adult day care facilities in 2001 and 2002. The study found there were 3,407 adult day care centers in the United States. They then surveyed providers to determine the kinds of services they provided, identify gaps in the current service delivery system and the issues that providers faced. All national and state statistics quoted in this section come from this study.

The adult day care model has existed for at least 30 years. Over half of all centers have been in operation for over 10 years. Growth in the adult day services industry is evident, with 26% of all adult day centers opening in the last five years.

Nationally however, growth in adult day care centers lags behind the need for the service. The study determined that 56% of the counties in the United States are underserved (1,770 counties out of a total of 3,141). The study concludes that the current population base of

ADC LENGTH OF OPERATION



National Adult Day Care Study/
Wake Forest University 2002

the United States could support a total of 8,520 adult day centers. Thus, there is a need for an additional 5,415 new adult day centers nationwide (1,424 in rural areas and 3,991 in urban areas).

To determine need for adult day care services, the study used the Weiler demand model, which is based on the number of people in a market that are over 65. This model determined that 1.25% of the population over 65 is in need and likely to chose adult day care services.[105]

MAJOR FINDINGS RELATED TO CONSUMERS SERVED[106]

- The two most prevalent conditions of those attending adult day care services are dementia (52%) and frailty associated with age (i.e., those who were 60 years of age or older and in need of assistance and supervision and/or at-risk of social isolation but without dementia) (41%).

- Individuals being served range in age from 18 to 109, with an average age of 72 and a median age of 75.

- 43% of participants need help with toileting, 37% need help with walking, and 24% need help with eating.

- Most people attending an adult day center live with an adult child (35%) or a spouse (20%). Only 11% lived alone.

- The average length of attendance at a center is two years.

- The number one reason for discharge from a program is placement in a residential setting (such as a nursing home or assisted living facility). The second most common reason for discharge is death. Decline in functional status and medical illness were the next most frequent reasons.

MAJOR FINDINGS RELATED PROVIDERS[107]

- 78% of adult day centers are not-for-profit organizations.

- 77% of centers are open Monday through Friday. The rest operate some period of time over the weekend.

- 82% of centers are open eight or more hours a day.

- 20% of centers are dementia specific (i.e., they serve people with Alzheimer's disease or other related dementias exclusively).

- Nationwide, the average hourly flat fee is $10, the half-day fee is $28, and the full day fee is $46. The average cost of providing care is $56/day. The median cost per day was $49.

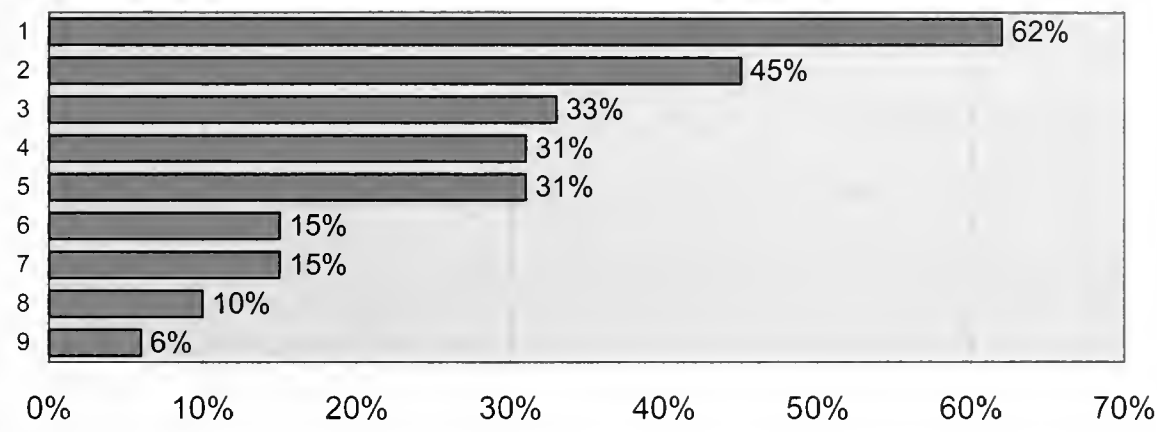
- On average, centers reported 38% of all revenue coming from third-party public reimbursements (mainly Medicaid Home and Community Based Waiver dollars).

- The percent of revenue from private pay participant fees was 35%.

- 13% of all revenue comes from Other Operating Revenue (private insurance, ancillary services and managed care) .

- 14% comes from Non-Operating Revenue (donations, grants, and fundraising).

MAJOR ISSUES FACING ADULT DAY CARE CENTERS



1 - Adequate Funding
2 - Recruiting/Retaining Qualified Staff
3 - Maintaining Adequate Census
4 - Transportation
5 - Public Awareness
6 - Adequate Space/Facility
7 - Participant Acuity
8 - Therapeutic Activities
9 - Licensing Activities

National Adult Day Care Study/Wake Forest University 2002

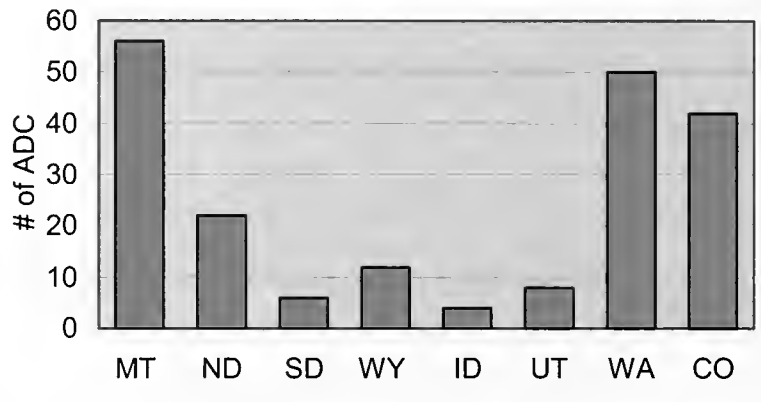
Financial issues top the list of major issues facing adult day care centers. Unlike other health care facilities, third party government reimbursement is not the main income source for adult day care centers. Centers must be flexible and competitive. Nearly half of centers (44%) reported having a deficit. Centers reporting a deficit were significantly more likely to have opened in the last 5 years (55%), compared with centers reporting a deficit that have been open over 10 years (35%). These economic stresses are closely tied to hiring and retention of staff at facilities.

MONTANA EFFORTS IN PROVIDING ADULT DAY CARE SERVICES

Because of their availabilty, adult day care is a way that many informal caregivers receive respite services in Montana. Under state law, an adult day care centers must be licensed by the state to operate. Centers are licensed as a health care facility. An adult day care center is defined as "a facility, freestanding or connected to another health care facility, that provides adults, on a regularly scheduled basis, with the care necessary to meet the needs of daily living but that does not provide overnight care." [108]

Montana has an abundance of adult day care programs. At the time of the Wake Forest University study, Montana had 56 licensed adult day care facilities. This was the most of any state in the Intermountain region or Pacific Northwest. In 2003, the number of licensed centers had increased to 65.

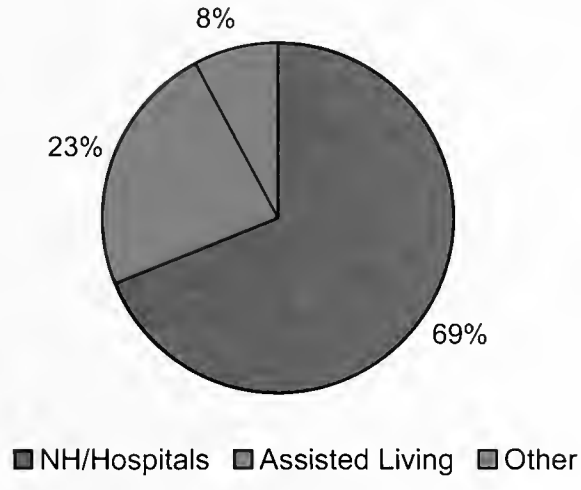
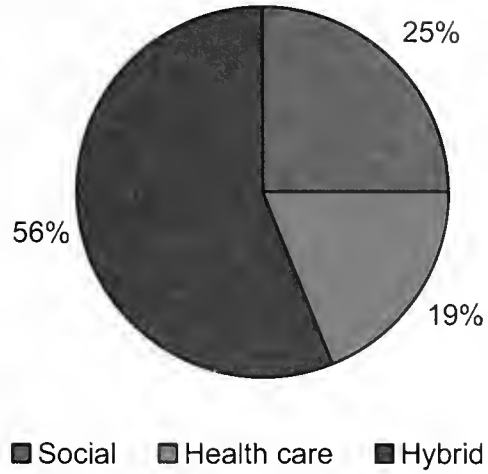
ADULT DAY CARE CENTERS BY STATE



National ADC Study/Wake Forest University 2002

Adult day care centers in Montana do not meet the average profile for facilities nationwide. Adult day care centers in Montana are much more likely to be operated by health care facilities. Over 90% of centers operated in Montana were part of health care facilities (nursing homes or assisted living facilities). This is a substantially higher rate than the national average of 27%. This is largely due to Montana's rural nature and low population density. Most health care providers that have adult day care programs offer them as a complement or a supplement to their primary mission. They are also more likely to be a hybrid of the social and medical model of service. Nationally, 42% of programs were a hybrid model, while 56% of adult day care programs in Montana used a hybrid model.

Adult day care centers in Montana tend to be smaller in size, have a lower utilization rate, have a higher daily cost to attend and a lower percentage of its income derived from third party payers than the national averages. At $83, Montana has the 4th highest unit cost per day for services. This is in part due to the small size of the programs in Montana. It also has the 4th highest percentage of people that are paying for adult day care out of their own pockets.

OPERATORS OF ADULT DAY CARE IN MT	MODELS OF CARE
	

National Adult Day Care Study/Wake Forest University 2002

The Wake Forest University study found that Silver Bow County was the only county in Montana that was underserved (i.e., it had a population large enough to sustain an adult day care center but had no center). Twenty five counties in Montana are without a center and based on their population are not large enough to sustain one. Thus, they were determined not to be underserved. These counties tend to be in the eastern part of the state. Twenty seven counties were deemed to have excess capacity (i.e., they do not have enough population to sustain the center that currently exsits). These facilities are able to exist because they are located in health care facilities and are supplemental services.

The following statistics compare Montana adult day care programs to national statistics.[109]

	U.S.	MONTANA
Underserved counties	56%	2%
% of facilities with enrollment of 20 or fewer	26%	100%
Average daily number of people enrolled	42	12
Average number of people attending	25	4
Average capacity per program	38	16
Average utilization rate (Attendance/Capacity)	66%	25%
Average unit cost per day	$56	$83
Average private pay fee	$46	$39
% of income from private pay	35%	79%

About 10 nursing homes have some agreement with County Councils or Area Agencies to provide institution based respite. Half of these facilities are in eastern Montana. This collaboration allows additional opportunities for caregivers to receive services and supplements existing nursing home programs. The only downside is that some caregivers and care recipients may be reticent to use nursing homes based services because of the stigma attached nursing homes or because the environment can be too stimulating for some care recipients, especially persons who have Alzheimer's disease.

The only freestanding adult day care program that received NFCSP funds was the program run by the Bozeman Senior Center. It had been in operation for five years before closing recently. The closure was due to declining usage and revenue as well as competition from institution based services.

5. SUPPLEMENTAL SERVICES

Supplemental services are meant to be short-term services provided to caregivers on a limited, short-term basis. Montana allows these funds to be used for skilled nursing services, personal care services, transportation, homemaker, home chore and home delivered meals. This option is used on a very limited basis in Montana.

Supplemental services typically augment funding for other service providers so they can provide services to caregivers who fall between the cracks. Area Agencies and County Councils can provide these services directly or contract for services. Area I, Area IV and Area V contract with public health nurses to provide skilled nursing services. Funds are used in caregiving situations where Medicaid or Medicare does not provide coverage.

Funds also are used to provide transportation in caregiving situations. This typically occurs in the area of medical transportation.

SUMMARY

SUMMARY

The establishment of the National Family Caregiver Support Program provided a focus on informal caregiving. It has also provided critical funding to begin to develop services to its intended target population. Efforts regarding the National Family Caregiver Support Program have resulted in new partnerships and collaborations, outreach to new populations, and provision of services to respond to the unique needs of informal caregivers.

The Aging Network was able to strengthen a critical service - its Information and Assistance Program. NFCSP funding was used to increase staffing in the I&A Program, which has allowed it to solidify the foundation of the program and at the same time expand services to caregivers. There is currently an Information and Assistance Coordinator in every Area Agency office. Increased staffing has provided manpower to develop additional educational, informational and supportive services that benefit caregivers. Because of increased awareness, caregiver issues have been incorporated into most of the educational and informational activities that occur at the state and local level. This was accomplished with relatively little funding. It has allowed the Aging Network to do additional outreach activities to identify and reach caregivers. I&A staff have also assisted in the development of support groups. Finally, starting federal fiscal year 2004, the state will implement a data collections system that will allow data analysis on caregiver demographics, resources used and unmet caregiver needs.

Respite services are available through most of the Area Agencies on Aging. The Aging Network has made great strides in providing respite. However, respite services were identified as the single largest unmet need by virtually all Area Agencies. The single greatest barrier to increasing respite services is funding. The Aging Network has had to be very resourceful in trying to develop local respite programs. Collaboration with lifespan respite programs and volunteer respite programs have increased services and strengthened these programs and increased services.

Research has shown that respite services must be used in sufficient amount to be effective. Additional funding for respite services will be necessary if it is to accomplish this goal. The fact that few respite programs have had to set limits on service, yet Area Agencies on Aging see it as the largest unmet need for caregivers would seem to indicate that more outreach and advertising needs to be done about available respite services. The Aging Network will also have to look at providing the service on a sliding fee scale basis or find other funding mechanisms if programs are to remain viable and serve those who are at greatest social and economic need.

FUTURE TRENDS

The future of informal caregiving will be affected by a number of demographic, cultural and health trends. The need for informal caregiving is certain to only grow. We cannot take for granted however, that current patterns of informal caregiving can be sustained. Of a number of factors that will make it difficult to sustain the same level of informal caregiving, the primary ones are:

- continuing high numbers of women employed full time;
- continued growth in the number of people requiring long-term care, mainly as a result of population aging;
- out-migration of adult children to urban centers for employment; and
- an increase in the proportion of persons age 85 and older, the group most likely to need long-term care.

As the population ages, primary caregivers (whether spouses or adult children) will be much older themselves on average, making them less able to provide the level of informal care they might have given when younger.[110]

The increasing participation of women in the paid work force, the postponement of marriage, the greater prevalence of divorce, and the increase in childbearing outside of marriage all have affected families. Increasing life expectancy has brought two major changes in family structure and function. First, more generations are alive at any one time, which increases the size and breadth of families. Second, the longer average life expectancy has increased the length of time families are likely to include a family member with an age-related disability. It is too soon to know how these changes will affect American family life. Much will depend on trends in disability among older Americans: the proportion of later life spent with a disability, the number of years an older person may need assistance with daily activities, and the age at which that assistance is needed. Because family members have traditionally provided care to elderly relatives, the need to care for frail family members who live to advanced ages may place a greater strain on family members, especially when adult children, nieces, or nephews are themselves beginning to suffer from age-related impairments. If, however, longer lives yield more years of good health, as recent trends suggest, older Americans may be able to play an active role in their families until very old ages.[111]

The baby boomers may be at the forefront of yet another phenomenon. Despite their numbers, baby boomers have had relatively few children, sparking concern that those who may need care or assistance in advanced age will have a small circle of immediate family to draw on.[112]

However, new research finds that the concept of family for the elderly of the 21st century will be very different from the makeup of families of the elderly today.

Unprecedented rates of divorce and remarriage are already redefining families of baby boomers. When the boomers become the elderly of the future, they will have impressive numbers of stepchildren and step grandchildren, expanding the numbers of family members on whom the disabled may rely, if needed. For the younger generation, these changes in family structure could increase the potential for caregiving responsibilities but also offer more opportunity to share any burdens among siblings. There may be a need to reconsider traditional views of support ratios for retirement and long-term care and to look more closely at the dynamics of intergenerational relationships generally.[113]

The following are some projections for caregiving needs of the current baby boom generation from researchers at the University of California, Berkeley.[114]

- Disability rates among older people are on the decline. But rapid growth is expected in the sheer number of the very elderly, those 85 and older, who are most in need of help.

- The relatively low birth rate among baby boomers will ultimately result in a steep decline in the numbers of elderly people with biological children. Today, 70 to 85 year-olds have on average 2.4 living biological children, but the 70 to 85 year-olds of 2030 will have on average only 1.6 biological children. Adding stepchildren to the mix changes things dramatically. Since 1980, the ratio of biological children to stepchildren for people 70 to 85 has doubled, and is expected to rise by another 50 percent by 2030.

- The number of biological grandchildren is expected to drop by 40 percent for 70 to 85 year-olds, from 4 grandchildren today to 2.4 on average by 2030. But the average goes back up to 4 in 2030 when step grandchildren are added in. At that point, older Americans will have one step grandchild for every 1.7 biological grandchildren.

- The number of "kin-deprived" elderly ages 70 to 85, those without living spouses, brothers, sisters, children, or stepchildren, will stay low well into the next century, at between 3 and 4 percent, in part due to increased life expectancy.

- The responsibility for care and support will increase for the younger generation nearing retirement in a little over 30 years. There will be fewer of the "younger generation" potentially sharing responsibility for more parental generation survivors. Today's ratio of around 2 to 1 will be 1 to 1 in 2030 for those in their 50s and parents 70 and up. But more people will know several generations of their own family; by 2030, more than 70 percent of 8 year-olds will likely have a living great-grandparent, if current trends in mortality hold steady or improve.

The dramatic change in the numbers, however, is not the whole story. The simple increase in numbers of people called "family" will not necessarily translate into the

willingness or ability to provide support for the elderly. The notion that stepchildren and step grandchildren of baby boomers will take on responsibility for their care may be optimistic, with the multiple responsibilities and geographic dispersion of potential caregivers. Researchers stress that how these relationships are likely to work in the future is critical, especially in light of a body of research showing that ties of step-relationships are generally much weaker than those of "blood" relatives.

The National Family Caregiver Support Program represents a first step towards meeting the needs of current and future caregivers. However, much needs to be done at the federal and state to create a comprehensive response to caregiver needs. At a national caregiver empowerment summit convened by the national Alliance for Caregiving in 2001, summit participants identified five points as categories around which specific policy solutions should be developed:[115]

Affordability

- Changing the way long-term care is financed by making caregiving more affordable for the middle class. Such a system could include a mix of subsidized insurance, private insurance, tax credits and deductions;

- Promoting consumer choice by giving stipends to family caregivers who choose to provide the care themselves and Social Security credits to those who leave the workplace to do full-time caregiving.

Availability

- Developing local information and referral programs, caregiver ombudsmen, caregiver registries, caregiver joint purchasing, and care management services so that consumers know where to turn for a variety of services;

- Developing enough programs and providers at the local level so that all communities have access to a range of caregiving services, such as information and referral, respite care, adult day care, and caregiver support groups and counseling; and

- Building a pool of trained paid caregivers large enough to meet the need.

These encompass the major challenges facing federal and state governments as the NFCSP is implemented.

The most controversial of these issues is whether to pay informal caregivers for providing care. This would seem to go against the basic definition of informal caregiving. Many policymakers and program administrators worry that expanding access to publicly funded services will result in the substitution of formal for informal care with government paying for an ever greater share of the assistance that has traditionally been provided by families "for free." It is often impossible to determine, in particular cases, whether publicly funded services are, in fact, substituting for informal

care that would otherwise have been available, or whether publicly funded services are necessary to compensate for an unavoidable lack of family caregivers. Controlled experimental design studies such as the National Channeling Demonstration have consistently found, however, that family members who have previously been providing services do not significantly decrease their efforts when publicly funded services become available. According to this and other caregiving research, when formal care is increased the care provided by families also increases. In other words, as care needs expand, formal and informal care increase together.[116]

Proponents of family pay believe that it promotes consumer control by expanding options; results in better quality care; is a good solution to the challenge of finding respite workers; allows care recipients to be cared for by people they trust; increases care recipient satisfaction; and provides people with a job who may have had to leave their previous employment because of caregiving responsibilities. Others worry that paying family members leads to expenditures for care that would otherwise have been free, can result in conflicts between care recipients and caregivers, and creates the possibility for family members to exploit care recipients. [117]

Some states have already developed income tax credits or exemptions as a way to encourage caregiving as well as to help family caregivers with the financial burden of caregivers. To date, 22 states have passed such laws. Tax relief for caregivers in form of caregiver tax credits were proposed as part of NFCSP but were dropped. Montana currently has a tax credit for caregivers providing care to an elderly dependent. However, usage has averaged only about 50 taxpayers per year over the last 10 years.

In an effort to reduce the fragmentation in the long-term care system in Montana, the Aging Bureau received a Real Choice Systems Change Grant for Community Living from the Administration on Aging and the Centers for Medicare and Medicaid Services to develop a pilot Aging and Disability Resource Center. The three year pilot program will operate in Yellowstone County and serve both adults age 60 and over and adults with physical disabilities. The goal of the project is to help people make informed decisions about their care options and serve as the single point of entry for both public and private-pay individuals in the need of long term care, their family members, or those planning for their long term care needs. The Resource Center will assist people in determining eligibility for long-term care options, benefits and employment options.

The Area II Agency on Aging and the Yellowstone County Council on Aging (YCCOA) will be responsible for the local implementation of the program. The YCCOA had developed a fulltime caregiver support position prior to receiving the grant. This position was one of the few full time positions in the state that was responsible for coordinating local caregiver activities. The caregiver support position will be housed in the new Aging and Disability Resource Center to coordinate caregiver activities with the new Center.

The results of this three year pilot program will be critical to the Aging Bureau, the Area Agencies on Aging and the County Councils on Aging, as they continue to address the challenges of provide comprehensive services in a frontier state.

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CAREGIVER RESOURCES

Family Caregiver Alliance
690 Market St, Ste 600
San Francisco, CA 94104
800.445.8106
http://www.caregiver.org/

Administration on Aging National Family Care Support Program Resource Center
http://www.aoa.gov/prof/aoaprog/caregiver/caregiver.asp

AoA ElderCare Locator
800-677-1116
http://www.eldercare.gov/

Alzheimer's Association
800.272.3900.
http://www.alz.org/Caregivers/overview.asp

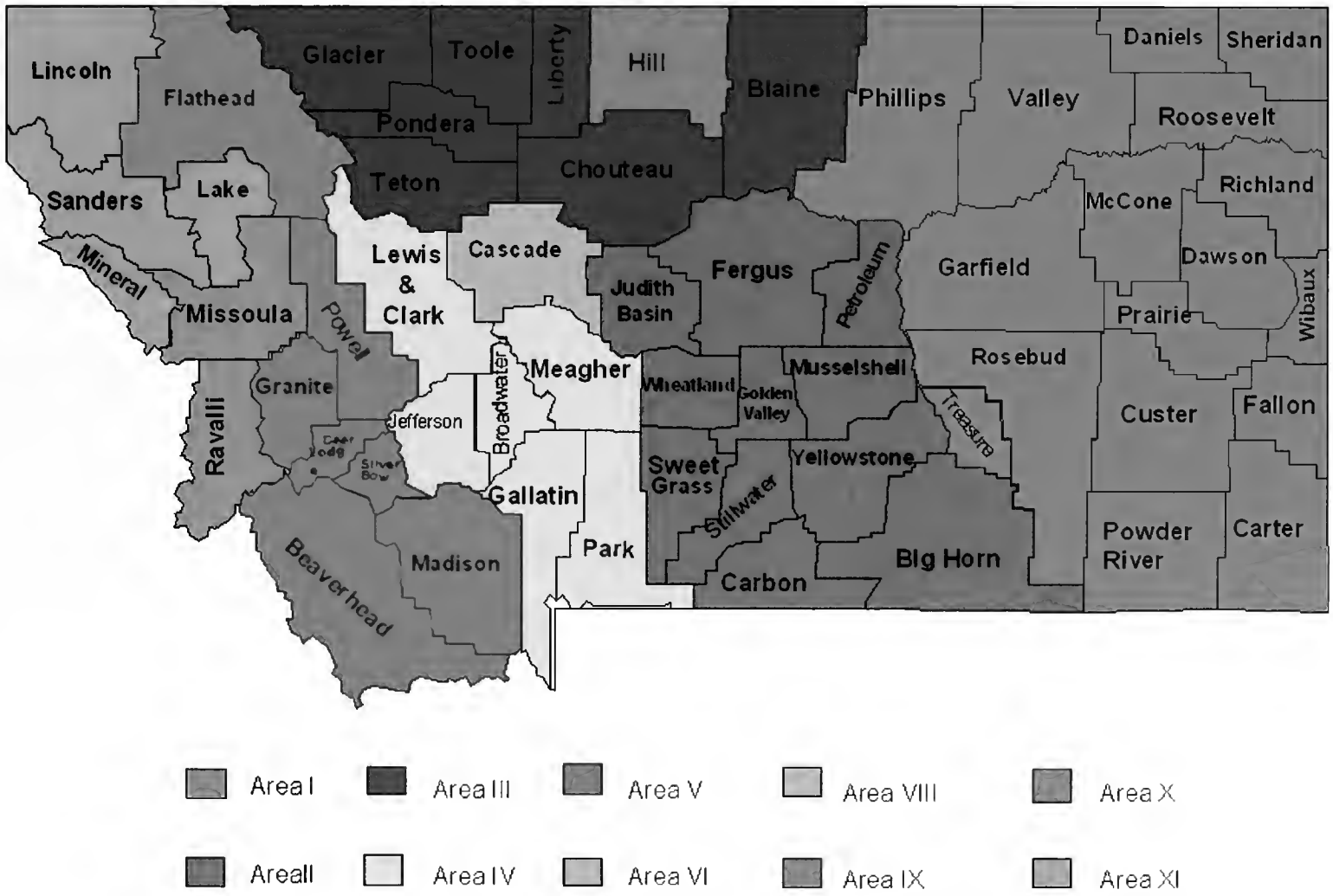
National Alliance for Caregiving
4720 Montgomery Lane
Bethesda, MD 20814
http://www.caregiving.org/

U.S. Senate Special Committee on Aging
G31 Dirksen Senate Office Building
Washington, DC 20510
Phone: 202-224-5364
http://aging.senate.gov/

Centers for Disease Control and Prevention
National Center for Health Statistics
Division of Data Services
Hyattsville, MD
20782
(301) 458-4636
http://www.cdc.gov/nchs/Default.htm

U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201
http://DHHS.gov/

Montana Area Agencies on Aging



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